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The experience of waiting for a kidney transplant from a deceased donor

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THE EXPERIENCE OF WAITING FOR A KIDNEY TRANSPLANT FROM A DECEASED DONOR

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TITANIA BURNS (RN, Grad Cert Acute Care Nursing (Renal))

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CERTIFICATION

I, Titania Burns, declare that this thesis, submitted in partial fulfilment of the requirements for the award of Master of Philosophy, in School of Nursing, University of Wollongong, is wholly my own work unless otherwise referenced or acknowledged. The document has not been submitted for qualifications at any other academic institution.

Titania Burns

June 2016

ABSTRACT

There are over 1100 people waiting for a kidney transplant in Australia, with an estimated 170,000 people waiting worldwide. Most of these people do not have a living donor, so their only option is to live on dialysis while they wait for a kidney from a deceased donor to become available. In Australia people wait for an average of 2.6 years to receive a kidney from a deceased donor, a similar length of time to other developed nations around the world. Existing literature has focussed on transplant outcomes and the experience of dialysis, but there is little published research that describes what it is like for people once they have been placed on the waiting list. Therefore the aim of this research is to fill this gap in the literature and provide an understanding of the experience of waiting for a kidney transplant from a deceased donor

The thesis includes a systematic review of the literature and a qualitative research study. Much of the existing evidence about waiting for a kidney transplant is reported incidentally in studies looking at the experience of living on dialysis. Synthesising these findings in a systematic review provided a baseline from which to conduct a qualitative study in order to produce findings that were exploratory and descriptive.

The study found that the experience of waiting for a kidney transplant took place in the context of living on dialysis. The thought of getting a kidney transplant gave people hope that they would escape from dialysis one day and return to a normal life. People lived with uncertainty about the timing of the transplant and whether or not it would be successful. Waiting for a transplant had a transformative effect on a person's relationships, enhancing their appreciation of family members who provided them with help and support; and resulting in new friendships with other people living on dialysis from whom they could learn and inform their own experiences. It also showed a complex response to the deceased donor who they hoped for, but who they also appreciated as a person in their own right.

The findings of this study are significant because they specifically explore the experience of a significant population about which little has been published. They may be used to develop interventions or further research to better support people in this population.

ACKNOWLEDGEMENTS

"Everything comes from you and we have given you only what comes from your hand." 1 Chronicles 29:14

This thesis has been made possible through the contribution of many people. Firstly I would like to thank the participants who gave up their precious time to come and take part in this study. For some the wait continues on, while for others the wait has ended and a new experience of living with a kidney transplant has begun. Their willingness to share their stories for this study is greatly appreciated. Also all the people who did not take part, but who provided the inspiration – both people who are waiting while living on dialysis and those who have got their transplants – "Good on you George"!

The contribution of my supervisors cannot be understated. Professor Ritin Fernandez is inspirational in the field of nursing research. She gave me the confidence to try and the motivation to keep on going. Dr Moira Stephens, the voice of reason, encouraged me to listen to what people were saying and see what is really there. For all the hours of time spent reading my words, advising, directing and suggesting I thank you both very much.

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Finally I would like to thank my family. My parents Ros and Jay De Witt who always hoped I would go to university. For my three sons John-Jo, Sam and Charlie and my husband Tim – thank you for keeping me on track, for encouraging me to keep going and for providing plenty of distraction to keep me from getting stale.

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

ANTHOLOGY OF PUBLICATIONS

Burns, T, Fernandez, R & Stephens, M 2015, 'The experiences of adults who are on dialysis and waiting for a renal transplant from a deceased donor: a systematic review', *JBI Database of Systematic Reviews & Implementation Reports*, vol. 13, no. 2, pp. 169-211

ANTHOLOGY OF PRESENTATIONS

'The experience of waiting for a kidney transplant from a deceased donor – a qualitative study', Tania Burns, Ritin Fernandez and Moira Stephens, poster presentation, Renal Society of Australasia National Conference, June 2016, Gold Coast, QLD

'The experiences of people who are waiting for a kidney transplant from a deceased donor', Tania Burns, oral presentation, Transplant Nurses Association National Conference, June 2014, Perth WA

'Waiting for a kidney transplant – what the literature tells us', poster presentation, Tania Burns, Ritin Fernandez and Moira Stephens, Transplant Nurses Association National Conference, June 2013, Sydney NSW

LIST OF ABBREVIATIONS

AKI	Acute kidney injury
ANZDATA	Australia and New Zealand Dialysis and Transplant Registry
APD	Automated peritoneal dialysis
AVF	Arteriovenous fistula
AVG	Arteriovenous graft
CAPD	Continuous ambulatory peritoneal dialysis
CARI	Caring for Australasians with Renal Impairment
CKD	Chronic kidney disease
CMV	Cytomegalovirus
COPD	Chronic obstructive pulmonary disease
CVAD	Central venous access device
CVD	Cardiovascular disease
DBD	Donation after brain death
DCD	Donation after cardiac or circulatory death
ECD	Extended or expanded criteria donors
ESKD	End stage kidney disease
ESRD	End stage renal disease
ESRF	End stage renal failure
GFR	Glomerular filtration rate
GHQ-28	General Health Questionnaire
HD	Haemodialysis
HHI	Herth Hope Index
HLA	Human leukocyte antigen
HRQOL	Health related quality of life
JBI	Joanna Briggs Institute

JBI-QARI	Joanna Briggs Institute Qualitative Assessment and Review Instrument
KDIGO	Kidney Disease Improving Global Outcomes
KDOQI	Kidney Disease Quality Outcomes Initiative
KDQOL-SF	Kidney Disease Quality of Life short form
KHA-CARI	Kidney Health Australia – Caring for Australasians with Renal Impairment
NHMRC	National Health and Medical Research Council
NHS	National Health Service (UK)
NODAT	New onset diabetes after transplant
NOMS	National Organ Matching System
PD	Peritoneal dialysis
PJP	Pneumocystis jirovecii pneumonia
PRA	Panel reactive antibody
QOL	Quality of life
RRT	Renal replacement therapy
SF-36	Medical Outcomes Study Short Form 36-item health survey
TSANZ	Transplantation Society of Australia and New Zealand

CHAPTER 1 **INTRODUCTION TO THE THESIS**

End stage kidney disease (ESKD) is life-limiting, chronic condition. In 2011 ESKD was the sixth-most common chronic cause of death in Australia behind cardiovascular disease, cancer, cerebrovascular disease, diabetes and chronic obstructive pulmonary disease (COPD) (Australian Institute of Health and Welfare 2014). Kidney transplantation is one of the treatment options for people with ESKD along with haemodialysis (HD) and peritoneal dialysis (PD).

In Australia people cannot join the waiting list for a kidney from a deceased donor until they commence dialysis (Transplantation Society of Australia and New Zealand (TSANZ) 2016). Donated kidneys are allocated by a computer algorithm that calculates the compatibility of an organ with a recipient. This means that it is possible for a person to receive an organ after a short time if a perfect match becomes available. It also means, however, that some people wait a very long time. On average people in Australia wait 2.6 years for a kidney transplant (Australia and New Zealand Dialysis and Transplant Registry 2015e). People on the waiting list for a kidney transplant must be ready to be called for a transplant at any time.

1.1 Aim of the thesis

The aim of this thesis was to explore the experience of living on dialysis while waiting for a kidney transplant from a deceased donor. Much of the existing research focuses on post-transplant outcomes, or on the experience of life on dialysis. How people tolerate the nebulous nature of waiting for a kidney transplant is an under-investigated area that is the focus of this thesis.

1.2 Structure of the thesis

The thesis is presented in the manner of a traditional research report, with introduction and background, literature review, method, findings, discussion and conclusion. The literature review is made up of two parts; a general literature overview and a qualitative systematic review of the literature relating specifically to the topic under investigation. In total this thesis contains eight chapters. This first introductory chapter aims to introduce the topic under investigation and describe the structure of the thesis.

Chapter 2 provides clinical information about chronic kidney disease (CKD) and its management. It includes information about the incidence and prevalence of ESKD, renal replacement therapy (RRT) options and comparisons between RRT modalities.

Chapter 3 describes a general overview of the literature which looks at ESKD more broadly and other topics related the experience of waiting for a kidney transplant. It seeks to provide context to the study by describing literature about waiting for other kinds of solid organ transplants, living with a chronic disease, uncertainty and the experience of waiting.

Chapter 4 is a qualitative systematic review of the literature that has been published in the JBI Database of Systematic Reviews in March 2015 (Burns, Fernandez and Stephens 2015). It provides a thorough and rigorous synthesis of the published literature relating specifically to this topic. Together with the broader review of the literature it clearly establishes that there is a gap in the literature about the experience of living on dialysis with ESKD while waiting for a kidney transplant from a deceased donor.

Chapter 5 gives a description of the methodological approach and theoretical framework adopted in the study, along with an explanation of the methods used for data collection and data analysis.

Chapter 6 presents the findings of the study. Following an introduction of the study participants the findings are organised into four themes that characterise the experience of waiting for a kidney transplant: life on dialysis is restrictive; waiting for a kidney transplant involves living with uncertainty; waiting for a kidney transplants positively and negatively impacts the dynamics of a person's social relationships; and managing feelings towards the deceased donor. Within those themes are subthemes including hope, fear and acceptance.

Chapter 7 synthesises the findings in the context of what is already known in the literature. It presents a description of the experience of living on dialysis while waiting for a kidney transplant from the perspective of the person who is waiting. The strengths and limitations of the study are reported along with implications for clinical practice. Chapter 8 then gives a summary of the study and presents the final conclusions of both the systematic review and the study.

CHAPTER 2 **CHRONIC KIDNEY DISEASE DIAGNOSIS AND MANAGEMENT**

This chapter provides background and context to the study by describing chronic kidney disease (CKD). It includes the physical effects of the disease, as well as the comparative risks and benefits of the various renal replacement therapy options. Incidence and prevalence data for CKD, end stage kidney disease (ESKD) and the transplant waiting list is provided.

2.1 Incidence and prevalence of CKD and ESKD

The prevalence of CKD is increasing around the world (Australia and New Zealand Dialysis and Transplant Registry 2015a; Rao, Casula and Castledine 2014; United States Renal Data System 2014b). This increased rate of CKD is believed to be linked to the growing number of people with obesity, hypertension, diabetes mellitus and to a generally ageing population (Eckardt et al. 2013). The application of the standardised Kidney Disease Improving Global Outcomes (KDIGO) classification system (KDIGO 2013) to large renal registry databases in Australia, Asia, Europe and North America has found that around 10% of the population have CKD (James, Hemmelgarn and Tonelli 2010) increasing to 20% among people over 60, and 35% among those over 70 years of age (Eckardt et al. 2013).

The number of people with CKD who progress to ESKD is estimated from national renal registries as the number of people who start renal replacement therapy each year (Australia and New Zealand Dialysis and Transplant Registry 2015a; Rao, Casula and Castledine 2014; United States Renal Data System 2014b). The incidence of new patients with ESKD starting renal replacement therapy in Australia has been relatively stable over the last five years at around 110 patients per million population (pmp) per year (Australia and New Zealand Dialysis and Transplant Registry 2015a), but the prevalence of people with ESKD in Australia has increased from 608 pmp in 2002 (McDonald 2002) to 928 pmp at the end of 2014 (Australia and New Zealand Dialysis and Transplant Registry 2015a). Similar increases in prevalence of ESKD have been observed in the United States (United States Renal Data System 2002, 2014b)and the United Kingdom (Ansell and Feest 2001; Rao, Casula and Castledine 2014).

At the end of 2014 there were 1123 people in Australia living on dialysis and waiting for a kidney transplant from a deceased donor (Australia and New Zealand Dialysis and Transplant Registry 2015e). Despite efforts to increase the transplantation rate, the most recent Australian data shows that in 2014 there were around 330 deceased donors

resulting in approximately 650 kidney transplants (Australia and New Zealand Dialysis and Transplant Registry 2015f, 2015g; Council of Europe 2014). As around 700 people in Australia join the waiting list each year, the number on the waiting list has not reduced significantly (Australia and New Zealand Dialysis and Transplant Registry 2015e). It is estimated that worldwide over 170,000 people are waiting for a kidney transplant (Australia and New Zealand Dialysis and Transplant Registry 2015e; Council of Europe 2014; NHS Blood and Transplant 2015; United States Renal Data System 2014a).

2.2 Definition and diagnosis of CKD

The kidneys perform many excretory and regulatory functions. The primary function of the kidney is to maintain fluid and electrolyte balance and excrete metabolic and toxic waste products. The kidneys also manufacture a range of hormones which sustain red blood cell production, blood pressure control, acid-base balance and calcium phosphate metabolism (Eaton and Pooler 2013; Eckardt et al. 2013).

The terminology in common use to describe the disease process and failure of normal kidney function refers to both the organ (kidney) and the functional system (renal) (Levey and Coresh 2002). Within the literature and around the world the words 'renal' and 'kidney' are often used interchangeably. Similarly the words 'disease' and 'failure' are also exchanged for one another, although 'failure' more specifically describes the impact of the disease on the functional status of the kidney (Johnson et al. 2013). As this thesis is being written in an Australian setting the terms chronic kidney disease (CKD) and end stage kidney disease (ESKD) will be used in line with the terms used in the Kidney Health Australia – Caring for Australasians with Renal Impairment (KHA-CARI) guidelines (Johnson et al. 2013) and which are widely used and understood within the field of renal care.

Chronic kidney disease is a progressive irreversible disorder defined by declining kidney function. A diagnosis of CKD is based on a measurable reduction in the function of the kidneys, and evidence of damage to the structure of the kidneys existing for a period of time greater than three months (Johnson et al. 2013). A single kidney contains approximately one to two million nephrons, each containing a glomerulus to filter the blood and tubules to reabsorb and balance fluid and electrolytes (Eckardt et al. 2013). The glomerular filtration rate (GFR) is used as a measurement of kidney function and is calculated based on the level of creatinine in the blood (Levey and Coresh 2012). A reduced GFR seen along with markers of kidney damage such as protein, albumin or blood in the urine, or abnormalities in imaging, indicates the presence of kidney disease (Johnson

et al. 2013). Where these changes last less than three months the disease is classified as acute kidney injury (AKI) (Langham et al. 2014), but where they continue for three months or more a diagnosis of CKD can be made (Eckardt et al. 2013). In 2002 the National Kidney Foundation's Kidney Disease Improving Global Outcomes group (KDIGO) developed a five stage system to categorise CKD (Levey and Coresh 2002). The classification system was revised in 2012 to include albuminuria and it is currently used to underpin the development of renal services and guidelines worldwide (KDIGO 2013). The KDIGO system of categories for the prognosis of CKD by GFR and albuminuria is illustrated in table 1 below.

Table 1: Prognosis of CKD by GFR and albuminuria categories KDIGO 2012

				Persistent albuminuria categories Description and range		
				A1	A2	A3
				Normal to mildly increased	Moderately increased	Severely increased
				<30mg/g <3mg/mmol	30-300mg/g 3-30mg/mmol	>300mg/g >30mg/mmol
GFR categories (mL/min/1.73m^2) Description and range	G1	Normal or high	> = 90			
	G2	Mildly decreased	60-89			
	G3a	Mildly to moderately decreased	45-59			
	G3b	Moderately to severely decreased	30-44			
	G4	Severely decreased	15-29			
	G5	Kidney failure	<15 or on dialysis			

Green: low risk (if no other markers of kidney disease, no CKD); Yellow: moderately increased risk; Orange: high risk; Red: very high risk
(KDIGO 2013, p.14) Reproduced with permission from KDIGO

2.3 The physiological effects of CKD

The physiological effects of CKD include high blood pressure (hypertension), anaemia, oedema, and abnormalities in the composition of the blood such as high potassium levels (hyperkalaemia), high phosphate levels (hyperphosphataemia), high levels of the metabolic waste product urea (uraemia) and deranged blood lipid levels (hyperlipidaemia) (Eckardt et

al. 2013). The person with CKD may experience symptoms such as altered patterns of urination, breathlessness, fatigue, nausea and vomiting, loss of appetite, pruritus, headaches and loss of libido (Johnson et al. 2013; O'Callaghan 2009).

Because CKD often develops slowly without significant signs or symptoms in the early stages, it is estimated that up to 90% of cases of CKD in Australia go unrecognised until the disease has progressed to stage three of the KDIGO system or beyond (Johnson et al. 2013). Some individuals lose 90% of their renal function before they notice any symptoms at all (Chadban et al. 2003; John et al. 2004)

Strategies for the management of the some of the physiological effects (both signs and symptoms) of CKD are listed in Table 2.

Table 2: Treatment of CKD

Symptom	Strategy
Hypertension	Anti-hypertensive medication (Phoon, Richard K. S. and Johnson, D. 2012)
Anaemia	Erythropoietin supplementation (McMahon and Macginley 2012)
Oedema	Restricted fluid intake (Phillips and Knuchel 2011)
Hyperkalaemia	Restricted dietary potassium intake and medical therapy (Chan and Chadban 2013)
Hyperphosphataemia	Restricted dietary phosphate intake and medical therapy (Chan and Chadban 2013)
Uraemia	Dialysis and medical therapy for symptom management (Koncicki et al. 2015)
Hyperlipidaemia	Lipid lowering medication (Phoon, Richard K. S. and Johnson, D 2012)

Chronic kidney disease is associated with higher incidence of comorbid disease and poorer outcomes than seen in the general population (Eckardt et al. 2013). Where CKD coexists with cardiovascular disease (CVD),the blood vessels, heart valves and soft tissues become calcified, contributing to higher than normal rates of death after myocardial infarction (Japanese Society of Nephrology 2009; Moe and Chen 2008; Ross and Banerjee 2013).

Other comorbidities of CKD include renal bone disease and an increased risk of cancers of the kidney and urinary tract (Danovitch 2010b).

The most severe stage of CKD is stage five, also known as end-stage kidney disease (ESKD). End-stage kidney disease is a chronic, life threatening condition said to occur when the GFR is <15ml/min/1.73m^2 or when renal replacement therapy is required in order to support life (Danovitch 2010b; Johnson et al. 2013).

2.4 Therapeutic options for people with ESKD

Once CKD progresses to ESKD, the individual will require some form of renal replacement therapy unless they have chosen not to pursue active treatment for their disease. End-stage kidney disease is a life limiting condition that if left untreated will result in the death of the patient. Broadly speaking there are two choices for people with ESKD: conservative care or active management with renal replacement therapy which includes haemodialysis (HD), peritoneal dialysis (PD) and kidney transplantation.

Before commencing any renal replacement therapy option, the risks and benefits of the therapy need to be considered. A table listing the comparable risks and benefits of each renal replacement therapy modality can be found in Appendix 1.

2.4.1 Conservative care

Renal conservative (supportive) care is a valid treatment option for people with high levels of comorbid disease or advanced age (Chambers, Brown and Germain 2010). It focuses on relieving symptoms, maximising quality of life and facilitating a good death (Brown et al. 2013). No difference has been found in the survival of people with ESKD who are over 75 years of age and who have a high level of comorbidity and who either have dialysis or do not have dialysis (Chandna et al. 2011). Interest in conservative care as a treatment option for individuals with ESKD has increased in recent years and is often offered with the support of a multidisciplinary renal supportive care service. This service comprises medical, nursing, social work and dietary expertise to provide a tailored, holistic package of care for each individual (Brown et al. 2015; Josland et al. 2012).

2.4.2 Haemodialysis

The aim of haemodialysis is to remove toxins and excess fluid through a combined process of diffusion and ultrafiltration. It achieves this by filtering the person's blood across a

semipermeable membrane (Daugirdas 2015; Kallenbach 2012). The first human haemodialysis took place in 1924, and the technology was gradually refined during World War II. The artificial kidney pictured below in figure 1 dates from 1943 and comprises a wheel made of wooden paddles wrapped in semipermeable cellulose which rotates through a large bath of dialysate fluid.

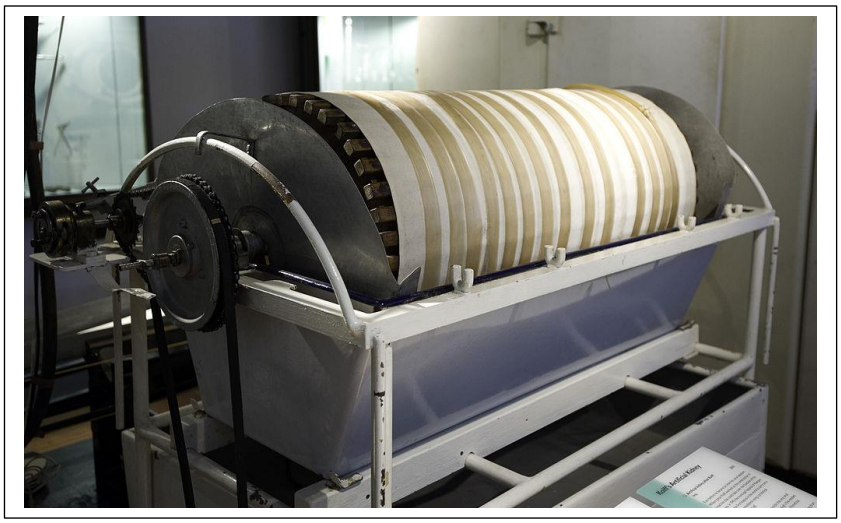

Figure 1: Kolff's Artficial Kidney 1943

(Koopman 2010)

Due to the challenges of developing a financially viable dialyser membrane and a reliable access to the blood stream, haemodialysis did not become a widely available treatment option until the 1960s (Eknoyan 2009; Kallenbach 2012). Current dialysis technology uses disposable dialysers containing thousands of hollow fibres made of semi-permeable membrane (Ahmad et al. 2015). Blood is pumped through the dialyser and waste products and excess fluid are removed by diffusion and ultrafiltration (Daugirdas 2015). A representation of a modern-day haemodialysis circuit is shown in figure 2 below.

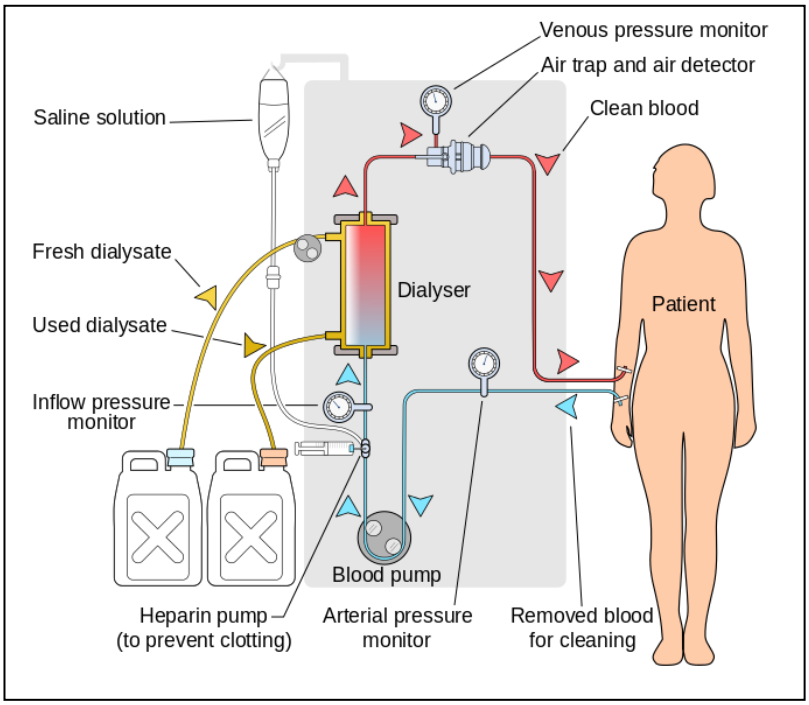

Figure 2: Haemodialysis

(Mrabet 2008)

The surgical creation of a vascular access is required to allow for large volumes of blood to be removed, filtered and returned to the body during haemodialysis sessions (Lopez-Vargas, P. and Polkinghorne, K 2012). There are currently three options for haemodialysis vascular access; arteriovenous fistula (AVF), arteriovenous graft (AVG) or a central venous access device (CVAD) (Polkinghorne et al. 2013). An AVF is created by joining an artery directly to a vein using the person's own blood vessels. The AVF is long lasting and has the lowest rate of morbidity and mortality of all the vascular access options (Lopez-Vargas, P. and Polkinghorne, K 2012). An illustration of an AVF is shown in figure 3 below.

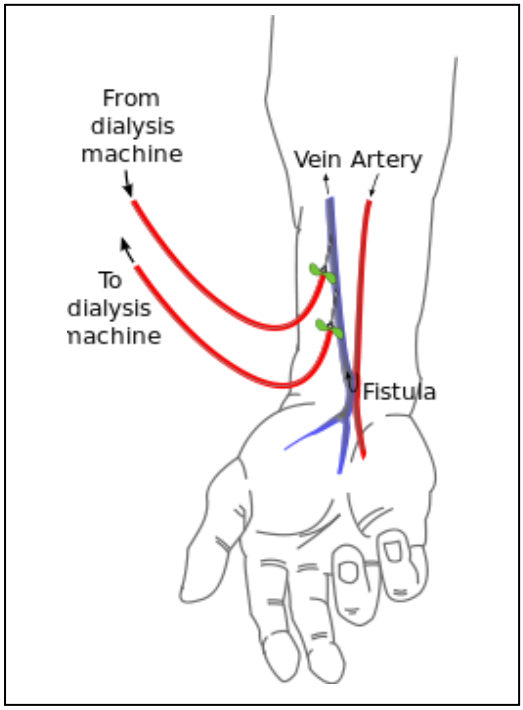

Figure 3: Arteriovenous fistula
(Kbik 2008)

Where the creation of an AVF is not possible the second option is to create an AVG by using a graft of synthetic material to connect the artery to the vein, illustrated in figure 4 (Konner 2005). Grafts do not have the longevity of the AVF and they have been shown to have an increased incidence of infections (Lopez-Vargas, P. and Polkinghorne, K 2012).

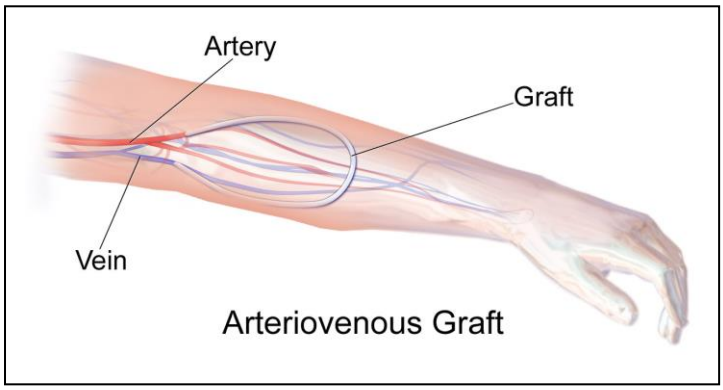

Figure 4: Arteriovenous graft
(Blaus 2014a)

For people who require haemodialysis urgently or for whom vascular surgery is not possible, a double lumen CVAD may be used (Santoro et al. 2014). Rates of infection with a CVAD are the highest of the three vascular access options (Lopez-Vargas, P. and Polkinghorne, K 2012). Figure 5 below shows a CVAD for haemodialysis.

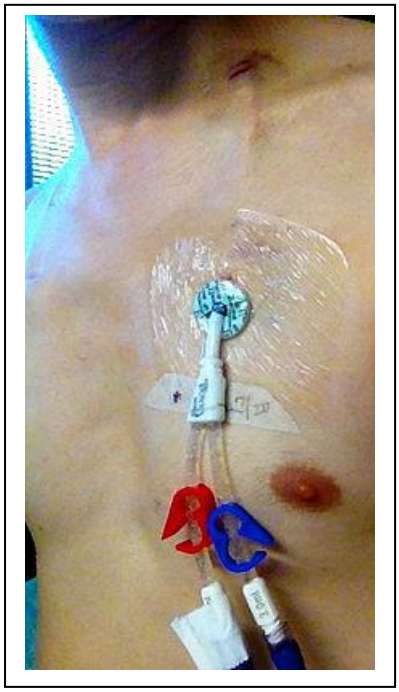

Figure 5: Central venous access device for haemodialysis

(Ludd 2013)

People on haemodialysis spend a minimum of 12 hours per week connected to the dialysis machine (Caring for Australasians with Renal Impairment 2005b) either at a hospital or satellite dialysis centre, or independently at home. During every dialysis session, access to the vascular system is achieved by the insertion of two large cannulas into the AVF/AVG (Vale, Lopez-Vargas and Polkinghorne 2011) or by accessing the CVAD. An aseptic technique must be maintained throughout because of the risk of causing bacteraemia (Lopez-Vargas, P. and Polkinghorne, K. 2012; Vale, Lopez-Vargas and Polkinghorne 2011). Bleeding is a potential complication of haemodialysis, either from a loose connection in the circuit, or through a cannula becoming dislodged. When removing the cannulas at the end of the haemodialysis session time must be taken to apply pressure to the site to ensure the bleeding has completely stopped (Faratro et al. 2015). Exsanguination from a haemodialysis access is a rare but serious occurrence that most commonly occurs at home and which causes death in approximately 40% of cases (Gill, Storck and Kelly 2012).

2.4.3 Peritoneal dialysis

Peritoneal dialysis uses the peritoneal membrane to remove toxins and excess fluid in a similar way to the dialyser membrane in HD (Blake and Daugirdas 2015; Danovitch 2010a). Metabolic waste is removed by diffusion while the addition of glucose to the PD fluid in differing concentrations creates an osmotic gradient for the removal of fluid (Blake and

Daugirdas 2015). Volumes of fluid are drained in and out of the peritoneal cavity through a surgically inserted, permanent PD catheter. The first PD treatment for a person with uraemia was performed in 1924 but it did not become a widely accepted treatment option for chronic ESKD until 1968 when the development of the Tenkhoff catheter provided a permanent, low irritant, long lasting peritoneal access device (Twardowski 2006). A diagrammatic representation of PD is shown in Figure 6 below.

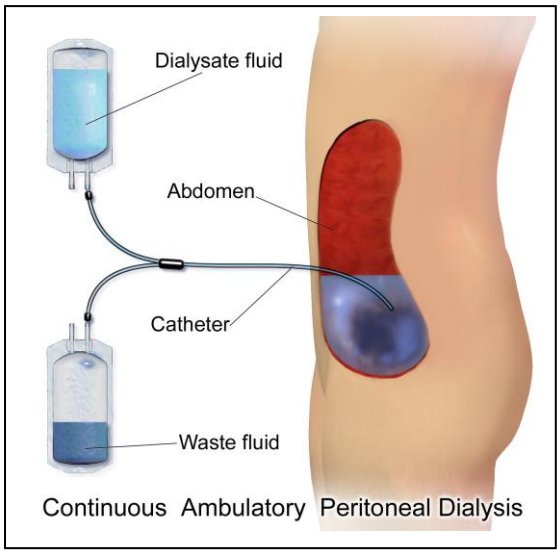

Figure 6: Peritoneal dialysis

(Blaus 2014b)

Peritoneal dialysis is prescribed for each person depending on their specific needs for fluid and solute removal. The PD prescription comprises of the composition and volume of the PD fluid to be used, the number of 'exchanges' or times that fluid has to be drained in and out in a 24 hour period, and the length of the 'dwell' which is the length of time the fluid sits in the peritoneal cavity before it is drained out (Crabtree and Jain 2015). Peritoneal dialysis is the first treatment option for many people as it can be more easily carried out independently at home, but it is not suitable for people who have had prior abdominal surgery, or who are unable to maintain meticulous standards of hygiene (Blake and Daugirdas 2015).

2.4.4 Transplantation

The third option for the active treatment of ESKD is kidney transplantation. This involves surgically grafting a donated organ into the person with ESKD and then preventing rejection of the organ by suppressing the immune response with medication (Mahendran and Barlow 2014). The first successful kidney transplant took place between identical twins in

1954 (Starzl 1990). By the early 1960's the development of immunosuppressive medications such as prednisolone and azathioprine resulted in the successful transplantation of organs from non-related and deceased donors (Mahendran and Barlow 2014). Advances in surgical techniques and medical therapies over the last 60 years have now made kidney transplantation a viable treatment option for many people with ESKD (Garcia et al. 2013). Modern medications are very successful at controlling the immune response and preventing rejection of the transplanted organ, but this does increase the likelihood of a person developing a life-threatening infection or cancer in the future (Helanterä et al. 2014; Wong, G. et al. 2013). Figure 7 below shows a diagram of the kidney transplant surgery, including the anastomosis of the blood vessels and ureter, and the native kidneys left in place.

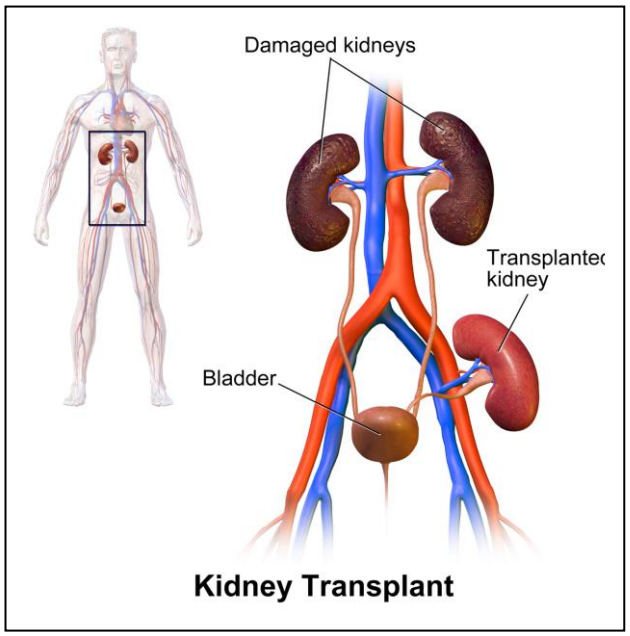

Figure 7: Kidney transplant

(Blaus 2015)

Kidney transplantation is recognised as the best RRT option in terms of survival, cost and quality of life (QOL) (Australia and New Zealand Dialysis and Transplant Registry 2015b; van Holder, van Biesen and Lameire 2014; von der Lippe et al. 2014). A full summary of the comparative risks and benefits of HD, PD and transplantation is presented in Appendix 1.

With a functioning kidney transplant people can live for many years without the restrictions on their lifestyle experienced by those on dialysis. Despite these benefits two barriers exist which prevent people from receiving kidney transplants. First is the suitability of the recipient to undergo transplantation and second is the availability of a donated organ. In

the next section the process of transplant suitability assessment is explained, followed by a description of organ donation and the process by which kidneys from a deceased donor are allocated to people on the waiting list.

2.5 Assessment for transplant suitability

Because of risks such as surgical complications and immunosuppression associated with transplantation, people wishing to receive a kidney transplant must first be assessed for their suitability. The assessment process includes consideration of the person's original kidney disease, cardiovascular health, history of malignancy and infectious disease, and an assessment of surgical suitability (Campbell et al. 2013; Mahendran and Barlow 2014). In Australia there are three criteria for entry to the transplant waiting list. First, the individual must have ESKD requiring dialysis. Second, they must have an anticipated low peri-operative mortality rate. Lastly, there must be an "anticipated 80% likelihood of survival at five years post-transplant" (TSANZ 2016, p. 40). Some countries allow people to join the transplant waiting list before they start dialysis, thus increasing their chances of getting a pre-emptive transplant and benefitting from the associated improved graft survival and quality of life (Davis 2010; Fissell et al. 2012). Other countries like Australia do not allow this as it further disadvantages individuals who are difficult to match by placing more people on the waiting list (Transplantation Society of Australia and New Zealand (TSANZ) 2016). However, pre-emptive transplantation with a donated organ from a living donor is permitted worldwide (Garcia et al. 2013).

2.6 Kidney donors

Donated kidneys come from one of two sources. Either a living person donates one of their kidneys to the recipient, or the organ is taken from a deceased person. Data shows that when a kidney is donated by a living donor the kidney transplant functions for a longer period of time and the recipient has a longer survival time (Australia and New Zealand Dialysis and Transplant Registry 2015f). The most recent Australian data shows that 95% of people and 90% of grafts survive to five years with a kidney from a living donor, compared to 89% of people and 81% of grafts from a deceased donor (Australia and New Zealand Dialysis and Transplant Registry 2015f).

2.6.1 Living donors

A living donor is a family member or a friend of the recipient whose motivation for donation is to alleviate the suffering of their loved one. Potential donors are screened

carefully to ensure the quality of the donated organ, and to assess the physical and psychological health of the donor in order to prevent problems in the future (Mahendran and Barlow 2014). Because of the lack of deceased donor organs, and because of the improved outcomes of living donor transplants, many initiatives have been developed to increase the pool of live donors including transplants from non-related donors (Terasaki et al. 1995), altruistic strangers (Clarke, Mitchell and Abraham 2014), blood group incompatible pairs (Muramatsu et al. 2014; Wyburn et al. 2010), and kidney exchange programmes for incompatible donor pairs (Ferrari et al. 2011; Ferrari, Woodroffe and Christiansen 2009; Garcia et al. 2013; Warren and Montgomery 2010).

2.6.2 Deceased donors

Deceased donors are people who have been declared brain dead but whose breathing and circulation are maintained by artificial life support (Escudero et al. 2015). Brain death is defined as, "a complete and irreversible loss of brain function" (Machado 2010, p. 9) and is clinically diagnosed on the basis of diagnostic criteria and confirmatory tests (Machado 2010; Munoz and Fox 2013). Because of the relatively small number of deceased donor organs available compared to the large number of people waiting for a transplant, strategies have been adopted to increase the number of deceased donors including donation after cardiac or circulatory death (DCD) (Manara, Murphy and O'Callaghan 2012) and the use of donors who were previously thought to been unsuitable, known as extended or expanded criteria donors (ECD)(Pesavento 2014).

2.6.3 Allocation of deceased donor organs

Globally the strategies used to allocate deceased donor kidneys vary according to locally agreed priorities. These include the age of the donor and the recipient, the presence of comorbidity in the donor and the length of time the recipient has spent on the waiting list. In Australia the allocation of organs from deceased donors is managed by the National Organ Matching System (NOMS) run by the Australian Red Cross (Clayton et al. 2013). When a kidney from a deceased donor becomes available the selection of a recipient takes into account multiple factors and is ultimately calculated by a computer algorithm. Factors which are considered include the person's blood group, their tissue type or human leukocyte antigen (HLA) matching, the level of HLA-antibodies to human tissue the person has in their body, and the length of time the person has spent waiting (Transplantation Society of Australia and New Zealand (TSANZ) 2016). In some cases special consideration is made for factors like age where the recipient is a child or a previous living donor in need of

a kidney transplant (Cecka et al. 2010; O'Connor et al. 2010). This mathematically generated selection process means that if a perfect tissue typing match is made, it is possible, although rare, for a person to receive an organ after waiting only a few months. However in people with high levels of HLA-antibodies it may be difficult to find an organ that does not cause a strong immune reaction. These people may have to wait for many years before receiving an offer (Wright 2011).

2.7 Waiting time

People waiting for a kidney transplant from a deceased donor are faced with a paradox. They must be ready at any time in case an organ becomes available, while being prepared for what will most likely be a long wait. Renal registry data and quantitative studies provide some information about estimated wait times and the effect of waiting on survival. The most recent reported data from Australia shows that in 2014 the median waiting time for a kidney from a deceased donor was 2.6 years (Australia and New Zealand Dialysis and Transplant Registry 2015e). This is similar to the US where the median wait time in 2013 was 3.6 years (United States Renal Data System 2014a), and in the UK in 2014 where it was 2.8 years (NHS Blood and Transplant 2015).

2.7.1 Impact of waiting time on patient and graft survival

The physical effects of waiting time for a kidney transplant have been investigated in a number of studies. In 1999 a longitudinal study by Wolfe et al. compared the rates of mortality in people who were on dialysis for ESKD over a period of six years from 1991-1997(Wolfe et al. 1999). Of the 228,552 people in the study, 46,164 were on the waiting list for a kidney transplant and 23,275 received a kidney transplant. The study found that the annual death rates in those three groups were 16.1 per 100 in people on dialysis, 6.3 per 100 in people on the waiting list, and 3.8 per 100 in people with a kidney transplant. People on dialysis, therefore, were 2.6 times more likely to die than those on the waiting list for a kidney transplant, while people on the waiting list were 1.7 times more likely to die than those with a kidney transplant. This finding was thought to reflect the selection process for transplantation suitability which screens out people who are less healthy.

An analysis of 73,103 transplants from 1988-1997 by Meier-Kriesche et al. in 2000 found that the longer a person spent on dialysis, the greater the risk of graft loss and death after transplantation (Meier-Kriesche et al. 2000). Spending more than four years on dialysis was shown to cause a 68% increased risk of graft loss and death than a person who

received a kidney pre-emptively before starting dialysis. Another study by Meier-Kriesche and Kaplan (2002) conducted a retrospective data analysis comparing the outcomes of 2,405 kidney pairs transplanted from 1988-1998 (Meier-Kriesche and Kaplan 2002). In this study kidney pairs were defined as organs from the same deceased donor where one kidney had been allocated to a recipient who had been on dialysis less than 6 months and the other had been allocated to a recipient who had been on dialysis more than two years. Acute rejection and delayed graft function were found to occur more frequently in the group who had been on dialysis more than 2 years, and those people also demonstrated poorer graft and patient survival outcomes. The assertion of this study is that "… waiting time on dialysis is the strongest modifiable risk factor for renal transplant outcomes" (Meier-Kriesche and Kaplan 2002, p. 1377).

Another retrospective cohort study from the same era compared the outcomes of 9130 transplants from living donors to recipients who had either been transplanted either pre-emptively, or who had been on dialysis prior to transplantation (Mange, Joffe and Feldman 2001). The study showed an increased risk of rejection in the first six months in people who had been on dialysis and overall better graft survival in people who had not received dialysis prior to transplantation. These findings were confirmed in an analysis of 112,249 transplants from 1999-2008 (Schold et al. 2010). The length of time spent on dialysis prior to transplantation was found to have a negative effect on graft survival outcomes. However, by adjusting for factors such as comorbid conditions, social class, income, access to health care and health literacy (Schold et al. 2010, p. 2014), the study found that dialysis did not have such a great effect as shown previously.

2.8 Conclusion

This chapter has described how the incidence of CKD and ESKD is increasing worldwide, with an estimated 170,000 people worldwide living on dialysis while waiting for a kidney transplant (Australia and New Zealand Dialysis and Transplant Registry 2015e; Council of Europe 2014; NHS Blood and Transplant 2015; United States Renal Data System 2014a). Treatment options for ESKD include haemodialysis, PD and kidney transplantation with a fourth option of conservative care for those who do not wish to pursue active therapy (Blake and Daugirdas 2015; Chandna et al. 2011; Danovitch 2010b; Daugirdas 2015). Each of the renal replacement therapy options has its own set of risks and benefits. Dialysis is effective for maintaining life in people with ESKD, but both haemodialysis and PD require large amounts of time to be invested in the treatment, with a dependence on a machine

that impacts many other areas of daily life (Hakim and Saha 2014). Kidney transplantation has been shown to offer the best physical health and QOL as well as being the cheapest long term option (Australia and New Zealand Dialysis and Transplant Registry 2015f). People who want a kidney transplant who do not have a living donor have no choice but to go onto the waiting list for a kidney from a deceased donor (Transplantation Society of Australia and New Zealand (TSANZ) 2016). People wait around three years on average for a kidney transplant from a deceased donor because the number of people waiting for a kidney far exceeds the number of organs that are available (Australia and New Zealand Dialysis and Transplant Registry 2015e; NHS Blood and Transplant 2015; United States Renal Data System 2014a). However because deceased donor organ allocation is based on tissue type matching it is possible, although very rare, that a person may receive a deceased donor organ after only waiting for a short time (Transplantation Society of Australia and New Zealand (TSANZ) 2016). Studies have shown that the length of time spent living on dialysis while waiting for a kidney transplant affects the rates of rejection and graft survival (Schold et al. 2010). The longer a person spends living on dialysis waiting for a kidney transplant, the poorer their post-transplant outcomes (Meier-Kriesche and Kaplan 2002; Wolfe et al. 1999). While this is helpful information, this quantitative data does not describe what the experience of waiting for a kidney transplant is like. In order to gain a fuller understanding of this paradoxical experience, the next two chapters will explore the literature, and particularly the qualitative data, in more detail to establish what is already known about the experience of waiting for a kidney transplant from a deceased donor.

CHAPTER 3 **BACKGROUND LITERATURE**

This chapter presents the literature that describes and informs the experience of waiting for a kidney transplant. Based on the background information an initial search of the Embase, Medline and PsychINFO databases was made. The initial search terms used were "wait*", "kidney", "renal" and "transplant*". Examination of the papers found in this preliminary search led to a series of themes and concepts being developed: living with chronic disease; the experience of waiting and strategies for managing a period of waiting; the passage of time; and uncertainty. The Embase, Medline and PsychINFO databases were searched again using these themes as search terms up to the current date in 2014. Decisions about whether to include the studies were based on whether or not they addressed the themes that had been identified. Reference lists were scrutinised for further relevant studies, and as the writing process went on newer studies were published which had cited one of the original papers found in the search. A total of 120 papers were included. The resulting summary of the literature provides a comprehensive overview of the experience of waiting for a kidney transplant from a deceased donor. The themes that emerged are used as headings and sub-headings in this chapter.

This chapter does not include literature concerned with post-transplant outcomes because the focus of this study is the pre-transplant waiting period. It also does not include studies about the experiences of people waiting for a transplant from a living kidney donor. Living kidney donation can be achieved by direct action on the part of both the donor and the recipient, and it often includes an emotional connection between the pair (Pradel et al. 2009; Udayaraj et al. 2012). Qualitative studies published from 1985 – 2013 about the experience of waiting for a kidney transplant from a deceased donor are presented as a systematic review in the following chapter.

3.1 The burden of living with chronic disease

Waiting for a transplant is an experience that occurs in the context of living with a chronic disease. The hope of a transplant is the hope for life without the chronic illness. Chronic conditions such as CKD are defined by their ongoing nature and irreversibility (Stewart and Sullivan 1982) and cause both a burden of illness and a burden of treatment (Sheilds et al. 2015; Tong et al. 2009). People living with chronic disease face the reality of their own mortality each day (Brown et al. 2006) as well as the erosion of their 'normal' lives that results in altered relationships and a poorer quality of life (Alshraifeen, McCreaddie and Evans 2014; Pierce 2014).

3.1.1 Burden of illness

Living with a chronic disease creates physical and psychological challenges, and many people live with multiple coexisting chronic diseases which impact their lives (Sheilds et al. 2015). In a study of people with chronic illness, Öhman et al. (2003) described how people viewed their bodies as a hindrance to the life they wanted to live (Öhman, Söderberg and Lundman 2003). Symptoms of pain and lethargy stopped them from achieving the most basic daily activities such as personal hygiene, sleeping and eating. Fatigue is a commonly reported symptom of chronic disease (Moens, Higginson and Harding 2014; Polaschek 2003b). Bonner et al. (2010) reported on the relationship between biochemical markers, fatigue and activity in people with CKD (Bonner, Wellard and Caltabiano 2010). Worsening renal failure, as indicated by the serum haemoglobin, albumin, phosphate and urea levels, was an indicator for greater fatigue and less activity.

The physical limitations of chronic disease mean that people are no longer able to invest time in the activities that had previously defined their sense of self, such as independent living, employment, education and social relationships (Bennett et al. 2013; Kuluski et al. 2014; Pierce 2014; Tong et al. 2013; Tong et al. 2009). As their strength and energy decrease, the increasing anxiety and depression can cause people to dwell on the meaning of their lives and develop a new image of themselves (Bjork and Naden 2008). Living with chronic illness has been described as a "loss of self" (Charmaz 1983, p. 168)or a "lost life" (Monaro, Stewart and Gullick 2014, p. 3262). Rather than expecting a return to health, people become immersed in the chronic disease experience. With no prospect of recovery they develop a new self-image that includes the disease (Charmaz 1983; Williams 1984). Bury described living with a chronic condition as biographical disruption that "involves a recognition of the worlds of pain and suffering, possibly even death, which are normally only seen as distant possibilities or the plight of others" (Bury 1982, p. 169). The concept of biographical disruption suggests that chronic conditions alter the normal course of life which would otherwise be expected to follow a series of culturally accepted milestones (Bury 1982) such as becoming independent and caring for others. Many people with chronic disease lose the expectation to get better and resume normal duties. Instead of focussing on recovery, they restructure their life to include the diagnosis and treatment of the disease as part of a new self-identity (Bury and Wood 1979; Charmaz 1983, 1994; Moore 2013; Stephens, McKenzie and Jordens 2014; Williams 1984).

In people waiting for a transplant the hope of returning to a normal life is not given up completely, but while they wait the restrictions of living with a chronic illness causes them to feel that that their lives are 'on hold' (Bjork and Naden 2008; Brown et al. 2006; Moran, Scott and Darbyshire 2011; Pierce 2014; Yngman-Uhlin, Fogelberg and Uhlin 2015). They live in a state of constant readiness understanding that an offer could come at any time, but they are repeatedly disappointed as weeks, months and years on dialysis go by (Pierce 2014). Rather than relinquishing the expectation of recovery, they experience feelings of powerlessness and acceptance as they continue to wait (Jonsén, Athlin and Suhr 2000; Pierce 2014; Yngman-Uhlin, Fogelberg and Uhlin 2015).

3.1.2 Burden of treatment

As well as the impact of the disease itself, the task of managing treatment regimen associated with chronic illness has also been described as burdensome. In a study of 97 people with various chronic conditions Sav et al. identified four themes regarding the burden of treatment (Sav et al. 2013). Firstly, the financial burden of paying for medications and treatment and the impact of that expense on the social, recreational and, in some cases, the basic daily living of the rest of the family. Second, the relentless time and travel burden of undergoing therapy and travelling to appointments. Third were the side effects, the inconvenience and the stigma of taking medication, in addition to the financial burden of buying the medicine. Finally was the healthcare access burden relating to problems people experience when accessing the healthcare system such as long waiting periods and the lack of continuity (Sav et al. 2013, p. 668-672). Sheilds et al. (2015) found that the experience of living with CKD was defined by, "the day-to-day intensity of managing symptoms and technologies" (Sheilds et al. 2015, p. 212). Once CKD progresses to ESKD, the technological requirements of dialysis therapy become all-consuming. The experience of living on dialysis has been called a "lost life" (Monaro, Stewart and Gullick 2014, p. 3262) or a "restricted life" (Clarkson and Robinson 2010, p. 31), while for those waiting for a kidney transplant it has been described as "being on hold" (Moran, Scott and Darbyshire 2011, p.505) and "life in standby" (Yngman-Uhlin, Fogelburg and Uhlin 2015, p. 1). These comments reflect those already mentioned relating to living with a chronic condition (Bjork and Naden 2008; Brown et al. 2006; Pierce 2014) and they show how hard it is for people to differentiate between the experience of the disease and the experience of the therapy itself (Tong et al. 2009). People on dialysis invest considerable effort in maintaining health, continuing in employment, carrying out family responsibilities and

paying for treatment (Bennett et al. 2013; Bonner, Wellard and Caltabiano 2010; Kuluski et al. 2014; Sav et al. 2013) as their dependence on dialysis encroaches upon everyday life (Herlin and Wann-Hansson 2010; Kaba et al. 2007).

3.1.3 Facing mortality

People who are living with a chronic condition while waiting for a transplant have been found to have a heightened sense of their own mortality (Brown et al. 2006; Jonsén, Athlin and Suhr 2000; Yngman-Uhlin, Fogelberg and Uhlin 2015). The effect of facing death was reported in one study as transformative (Brown et al. 2006), although participants also worried that they would not survive long enough to receive a transplant and were very aware of the effects of their chronic disease continually eroding their health while they waited (Brown et al. 2006; Jonsén, Athlin and Suhr 2000; Yngman-Uhlin, Fogelberg and Uhlin 2015).

Fear of death has been linked to increased anxiety in people with ESKD (Li et al. 2012; Silva et al. 2014). Not thinking about death (Calvey and Mee 2011; Öhman, Söderberg and Lundman 2003), or talking about death may be viewed as a strategy to avoid facing one's own mortality (Baines and Jindal 2003). It has been suggested that there is a culture of not speaking about death within the community of people on dialysis, perhaps because admitting to someone else's mortality means that people have to face the possibility that the same thing could one day happen to them. (Baines and Jindal 2003; Sheilds et al. 2015).

In a narrative enquiry by Sheilds et al. (2015) a group of participants with CKD showed an awareness that their illness was life-limiting and that without dialysis they would die. However, there was felt to be an expectation in the dialysis setting that talking about death was inappropriate and that they should rather focus on the life-saving technology (Sheilds et al. 2015). In this study people with CKD rarely discussed death with their family or treating doctors although they were well aware of it, having seen people in the dialysis unit decline in health and die (Baines and Jindal 2003) and having experienced times when they were been close to death themselves (Sheilds et al. 2015).

As well as facing the reality of their own mortality, people waiting for a transplant also have to manage their feelings towards the deceased donor. People struggle with the moral guilt of waiting for someone to die and they question their own merit to receive something that has come at such a great cost (Tong et al. 2015). In a qualitative study of 35 heart and kidney transplant recipients, participants admitted that during their wait they sometimes

wished that a suitable donor would die (Sanner 2003). Feelings towards the donor included sorrow for the family's loss, gratitude, indebtedness and guilt which were managed by avoidance, denial and suppression (Sanner 2003).

3.1.4 Altered relationships

The experience of living with a chronic disease has been found to cause people to feel socially isolated and lonely (Monaro, Stewart and Gullick 2014; Öhman, Söderberg and Lundman 2003; Tong et al. 2009). In part this may be because the physical limitations of the disease mean that people are no longer able to invest time and energy in maintaining social relationships (Bonner, Wellard and Caltabiano 2010; Herlin and Wann-Hansson 2010; Kuluski et al. 2014; Pierce 2014). Also by limiting what people are able to achieve, chronic illness may change the way they are perceived by others (Brown et al. 2006). Long-term chronic conditions have been shown to cause intolerance among friends and family when the person fails to get well (Bury 1982) and may lead to people living restricted and socially isolated lives, feeling discredited and burdensome to others (Charmaz 1983, P. 168). People with a chronic condition may feel they are viewed as hypochondriacs because they continue to have the same symptoms and problems (Stewart and Sullivan 1982). Michael (1996) reported that people felt a "loss of connectedness" and found it difficult to relate to others as they had done prior to their diagnosis (Michael 1996, p. 256). In some cases these feelings of isolation are exacerbated by people living with a chronic condition choosing to withhold information from their loved ones in order not to burden them (Monaro, Stewart and Gullick 2014; Öhman, Söderberg and Lundman 2003; Tong et al. 2009).

3.2 Waiting for a transplant gives hope

A kidney transplant offers the hope of life without restriction and with the freedom to follow any path (Charmaz 1991; Tong et al. 2015). Hoping for a transplant (Dekkers, Uerz and Wils 2005; Hagren et al. 2001; Herlin and Wann-Hansson 2010; Polaschek 2000; Polaschek 2003b; Rittman et al. 1993) allows people to believe that one day they will re-gain something approaching the normal life they had before they were sick (Calvey and Mee 2011; Moran, Scott and Darbyshire 2011; Yngman-Uhlin, Fogelberg and Uhlin 2015), free from the constraints of dialysis (Sadala et al. 2012).

> *"The young revealed hope in soon having a kidney transplant: dreaming of a future free from catheters, from bags and from the dialysis machine the hope of freedom, the hope to live a normal life"* Sadala 2012, p.72.

Yngman-Uhlin et al. (2015) interviewed eight people who were waiting for a kidney transplant while living on haemodialysis in Sweden (Yngman-Uhlin, Fogelberg and Uhlin 2015). They found that the thought of a getting a kidney transplant gave people hope of relief in the future while feeling 'tied up' by the dialysis treatment. In a qualitative, phenomenological study of the experiences of 16 people living on haemodialysis in the Republic of Ireland, Moran et al. (2011) found that a transplant was viewed as a "light at the end of the tunnel", enabling people to endure the dialysis therapy (Moran, Scott and Darbyshire 2011, p.504). The same phrase, "a light at the end of the tunnel" was used in Pierce's phenomenological study of people waiting for a liver transplant (Pierce 2014, p. 89) and Calestani et al.'s (2014) qualitative study of people's attitudes to being listed for a kidney transplant (Calestani et al. 2014, p. 2146). Transplant was viewed as a means of returning to 'happiness and health' (Pierce 2014, p. 89), holding the promise of a return to normal life (Calestani et al. 2014). In another study of 14 people waiting for a liver transplant in Sweden, the experience of being activated on the waiting list elicited feelings of relief because it gave people the hope of getting a transplant one day (Jonsén, Athlin and Suhr 2000). Likewise Bjork and Naden's (2008) report of the experience of 21 people waiting for a liver transplant in Norway found that the thought of a transplant gave them hope for the future tempered with concern about the operation (Bjork and Naden 2008).

3.3 Waiting for a transplant and health related quality of life

Health related quality of life (HRQOL) is a concept that aims to quantify a person's wellbeing. Individuals score their personal sense of wellbeing across number of 'domains' such as physical, emotional and social health, work life, sexual function, family adaptation and social support. Scores are then compared between different subsections of the population to evaluate HRQOL. Various tools have been developed to measure HRQOL including the Kidney Disease Quality of Life short form (KDQOL-SF) (Hays et al. 1994), the Medical Outcomes Study Short Form 36-item health survey (SF-36)(Ware Jr and Sherbourne 1992), the Karnofsky performance index, the General Health Questionnaire (GHQ-28), the Multidimensional Scale of Perceived Social Support, the Herth Hope Index (HHI) and the Sickness Impact Profile (Alshraifeen, McCreaddie and Evans 2014; Gomez-Besteiro et al. 2004; Landreneau, Lee and Landreneau 2010). Use of these quality of life

(QOL) measurement tools in the population of people with ESKD has been reviewed (Butt et al. 2008; Cagney et al. 2000) and many have been validated for use in this patient population (Barotfi et al. 2006; Gomez-Besteiro et al. 2004).

In a study comparing the HRQOL scores of people on dialysis with those of the general population, people on dialysis report lower scores, and therefore a poorer quality of life (Alshraifeen, McCreaddie and Evans 2014). The physical domains are affected the most, reflecting the effect of the chronic condition on a person's physical health. The more severe the person's symptoms, the poorer their perceived HRQOL (Carr et al. 2009). When comparing the HRQOL scores of people on haemodialysis, people on PD and those with a functioning kidney transplant, people with a transplant report higher scores than those on either dialysis modality (Bohlke et al. 2008; Landreneau, Lee and Landreneau 2010; Liem et al. 2007; Overbeck et al. 2005). In terms of HRQOL, kidney transplantation is the best renal replacement therapy option.

The effect of waiting for a kidney transplant has been evaluated by comparing the HRQOL scores of people who are on dialysis and either listed or not listed for transplant. Østhus et al. (2012) conducted a study into the relationship between acceptance on the transplant waiting list, HRQOL and depression (Osthus et al. 2012). Health related quality of life was measured in 215 people in Norway using the KDQOL-SF version 1.3 (Hays et al. 1994) and depression was assessed using the Beck Depression Inventory (Beck et al. 1996). The study found less depression and better HRQOL scores in the 122 people who had been accepted onto the transplant waiting list, compared to the 93 who had been rejected. Likewise, Santos (2011) in a study of 161 people undergoing haemodialysis therapy in Brazil found that people who were not waiting for a transplant had poorer HRQOL scores in both the physical and the emotional domains (Santos 2011). Being on the waiting list for a kidney transplant is associated with less depressive symptoms and better HRQOL scores than those who are not wait listed (Szeifert et al. 2012). These findings may reflect the transplant selection criteria (Transplantation Society of Australia and New Zealand (TSANZ) 2016) which pick out healthier people with less physical co-morbidities.

In contrast, a study by Lin et al. (2010) of 335 people in Taiwan who were either waiting or not waiting for a kidney transplant, found that the group waiting for a transplant had lower overall life satisfaction scores than those who were not waiting (Lin et al. 2010). This was felt to be because of the long waiting times and uncertainty about the impending surgery and long-term outcome. Despite being healthy enough to be listed for a kidney transplant,

anxiety about the future weighed people down and was evident in their life satisfaction scores. Low HRQOL scores have been linked to depression and anxiety (Franke et al. 2003).

Anxiety and depression are commonly reported symptoms in people who are waiting for a transplant. Anxiety is due to an awareness people have that they might die before the transplant comes up, or that their disease might progress too much for them to continue waiting (Jonsén, Athlin and Suhr 2000). People are mindful of time running out and they experience anxiety about the future success of their transplant (Yngman-Uhlin, Fogelberg and Uhlin 2015). Also the restrictions of living with a chronic disease while waiting for a transplant gives rise to feelings of sadness, depression and anxiety (Bjork and Naden 2008; Brown et al. 2006; Jonsén, Athlin and Suhr 2000; Moran, Scott and Darbyshire 2011; Pierce 2014; Yngman-Uhlin, Fogelberg and Uhlin 2015). Participants express fluctuating feelings, from "elation to despair" (Brown 2006, p. 127) as they wait day by day. The initial hope and excitement of being on the list to get a transplant is overcome by feelings of depression and discouragement as the waiting time continues (Brown et al. 2006). Where there is a lack of communication, frustration and anxiety increase as people feel forgotten (Brown et al. 2006; Jonsén, Athlin and Suhr 2000; Yngman-Uhlin, Fogelberg and Uhlin 2015; Yorke and Cameron-Traub 2008).

People waiting for a kidney transplant experience depression and anxiety at similar rates to other people on dialysis. A study by Chilcot et al. (2014) found that approximately 25% of people with ESKD experience symptoms of depression, including people on dialysis, transplant recipients and those waiting for a transplant (Chilcot et al. 2014). Li et al. (2012) conducted a study of 442 people waiting for a transplant in Hong Kong and found that 23.5% of participants reported a low or very low level of happiness (Li et al. 2012). The lower a person's expectation of getting a transplant, the lower their happiness score. Depression was related to concerns about their illness, the dialysis therapy, social isolation, fears of burdening their family and ideas of impending death.

Spending a longer time on dialysis and on the waiting list is associated with higher levels of stress and anxiety (Silva et al. 2014). In a study of 50 people in Brazil who were on the waiting list for a kidney transplant 56% of the group showed signs of stress and 60% showed anxiety with 30% having scores that indicated severe anxiety (Silva et al. 2014). These findings are similar to a study by Corruble et al. (2010)of 390 people in France who were assessed for anxiety and depression at the time of going onto the waiting list and then again at 12 months of waiting, 24 months of waiting and 3 months after

transplantation (Corruble et al. 2010). The study found that anxiety and depression increases during the waiting period and drops markedly after the transplant takes place.

3.4 The experience of waiting

It has been suggested that "waiting puts people at the mercy of another's schedule" (Mulcahy, Parry and Glover 2010, p. 1063). People waiting for a kidney transplant are at the mercy of a computer algorithm and an unknown donor. They are waiting for something specific that will occur at an unknown time. The literature about waiting encompasses waiting for events with a definite end point and waiting for indefinite events that may never happen. All of this is relevant to the experience of waiting for a kidney transplant.

3.4.1 Definite waiting

Some forms of waiting have an expected definite end point and the person entering into the wait knows from the start how long they will be waiting. Definite waiting includes waiting for news such as the results of exams or medical tests (Sweeny 2012; Sweeny and Andrews 2014; Sweeny and Cavanaugh 2012; Sweeny and Krizan 2013) or waiting for scheduled surgery (Carr et al. 2009; Carr, Teucher and Casson 2014; Johnson, Horwood and Gooberman-Hill 2014 {Sjöling, 2005 #812). None of these experiences are exactly like the experience of waiting for a kidney, because they do not include the emotional level of waiting for a donor to die. However the findings can be applied to the situation of waiting for a kidney transplant because they provide information about how people respond when they are waiting and when there are delays to the expected outcome.

Research in the workplace found that unexpected delays in a situation where there was a predicted end point caused people to lose the sense of being in control, leading to negative feelings (Guenter, Hetty van Emmerik and Schreurs 2014). The negative feelings were found to be greater if someone or something was identified as the reason for the hold-up, whereas if it was perceived as just 'bad luck' the delay was tolerated more easily. It was also shown that providing information about the prospective length of the delay and the cause of the delay gave a better sense of control and an improved experience of waiting. This finding was confirmed in a study of train passengers by Cheng and Tsai who also found that negative emotions were reduced by providing information and by apologising about the length of the wait (Cheng and Tsai 2014).

In a systematic review of studies looking at the patient perspective of waiting for scheduled surgery, Carr et al. found a relationship between quality of life (QOL) while waiting and the severity of the person's symptoms. They found that the greater the degree of impairment, the poorer the QOL with waiting described as stressful and causing anxiety among participants (Carr et al. 2009). In one of the included studies (Sjöling et al. 2005), waiting for surgery was described as like living "in 'no man's land' – waiting to return to a more normal life", and as being "… on hold – a continuous struggle against a faceless system" (Sjöling et al. 2005, p. 541-542). A study by Carr et al. (2014) found that people waiting for surgery reported that time seemed to go slowly when they experienced pain or distress, or could not carry out their day to day routines as normal or when they felt out of control. However where people had greater autonomy and more ability to carry out normal activities, the time of waiting seemed to speed up and the date for the surgery came around quicker than expected (Carr, Teucher and Casson 2014).

These examples show that even waiting for something with a definite endpoint causes people to feel out of control, stressed and anxious (Carr, Teucher and Casson 2014). The negative feelings caused by waiting can be reduced when people understand how long they are likely to wait and what is the reason for the delay (Cheng and Tsai 2014). When people are able to continue with their normal routines they have a better QOL (Carr, Teucher and Casson 2014). Waiting for a kidney transplant is not an example of a wait with a definite endpoint, but these insights are nevertheless helpful as they show what it is that people experience while they wait.

3.4.2 Indefinite waiting

Some types of waiting do not have a definite endpoint, but are unpredictable and indefinite. This includes not only waiting for transplants (Naef and Bournes 2009) but other surgeries where the date is not certain (Johnson, Horwood and Gooberman-Hill 2014), as well as living with cancer (Bailey, Wallace and Mishel 2007; Jowsey, Ward and Gardner 2013; Lovgren, Hamberg and Tishelman 2010; Mulcahy, Parry and Glover 2010) or another terminal diagnosis (Ellingsen et al. 2013; Lovgren, Hamberg and Tishelman 2010; Zhou 2010) and waiting for attention by people in long term care facilities (Mitchell et al. 2005).

In a study of people waiting for a lung transplant Naef and Bournes (2009) made three findings. Firstly, waiting is frustrating and difficult. Individuals are constrained and restricted while they wait, weighed down with lives 'on hold'. The second finding concerned the hope of the transplant that people waited for. Keeping a firm image in their

minds of what the transplant would do for them when they got it was part of the experience of waiting. Thirdly, 'fortifying engagement' described the activities and relationships people undertook while they waited. These helped participants to endure while they waited and included keeping busy, faith in God and relationships with family, friends and other people who were waiting {Naef, 2009 #693}.

Transplantation is not the only type of surgery where the wait is for an indefinite length of time. Johnson, Horwood and Gooberman-Hill (2014) conducted a study of people waiting for hip replacement surgery in the UK where the constraints of the health care system meant that the date was often rescheduled. In this study the participants felt that the time they spent waiting for surgery was lost time. They "… spoke of inability to make plans and of impatience and eagerness to have the operation as soon as possible" (Johnson, Horwood and Gooberman-Hill 2014, p. 130). The authors found that participants, "… 'put off making decisions' and faced an uncertain future, over which they lacked control" (Johnson, Horwood and Gooberman-Hill 2014, p. 130).

People with cancer endure a cycle of "waiting for diagnosis … for treatment … for remission … for relapse" (Mulcahy, Parry and Glover 2010, p. 1065-6) which is outside of anyone's control and cannot be predicted. Waiting was described as the "worst part of the cancer experience", and felt like living "… on someone else's schedule" (Mulcahy, Parry and Glover 2010, p. 1065-6). Hajdarevic, Rasmussen and Hörnsten (2014) found that in the initial stage of the cancer experience people felt uncertain and "groundless", followed by "searching for solid ground", going on with normal routines and re-evaluating priorities (Hajdarevic, Rasmussen and Hörnsten 2014). The impact of the disease upon the time and energy available caused people to re-evaluate their priorities and invest in the relationships and activities that were most important to them while they waited (Zhou 2010).

In a study of the lived experience of waiting among people in long-term care, Mitchell et al. (2005) found that waiting made people feel angry and upset, afraid of being forgotten and robbed of their self-worth (Mitchell et al. 2005). Activities that filled their time and occupied their minds made waiting easier to endure, as did the attitude they chose to adopt while they waited. Participants learned to live with the experience of waiting and accept it as inevitable, not as a personal punishment.

Waiting for a kidney transplant is a wait of unknown length combined with an uncertain outcome of either successful surgery, or graft failure and return to dialysis, or even death.

As waiting is an experience of the passing of time, the next section of the chapter will explore the different ways that the concept of time is described in the literature.

3.5 The experience of the passage of time

Waiting is an experience of time, and therefore an examination of the literature describing the different ways people experience the passing of time is relevant to appreciate the experience of waiting for a transplant. The concept of time has been examined over many centuries and researchers have developed different perceptions of what time is and how it passes (Jowsey 2015). Some of the ideas and concepts about time that are particularly relevant to the experience of waiting for a kidney transplant are those of; linear time (Barbour 2009), embodied time (Davies 1994), and liminality (Turner 1977). Each of these concepts is described below.

3.5.1 Linear time / clock time

Isaac Newton in Mathematical Principles of Natural Philosophy (1687) describes time as linear, something that passes from one moment to another and that is measurable by means of the movement of the planets, or of a man-made clock (cited in Barbour 2009, p. 2). Commonly measured in hours and minutes, it is also referred to as 'clock time' (Davies 1994). Two studies reported that people waiting for a transplant understood the information that they were given about the *average* waiting time to mean the *actual* length of time they would have to individually wait (Moran, Scott and Darbyshire 2011; Yngman-Uhlin, Fogelberg and Uhlin 2015). This is an example of using clock time to measure an event that is not easily defined in days and hours. The disappointment that people feel when they wait longer than the average indicates that there are different ways of describing the passage of time that may be more appropriate in the experience of waiting for a transplant.

3.5.2 Embodied time

While clock time is a convenient way to measure time, life events happen within a certain context and in relationship with other people (Valtteri and Dan 2014). Within these situations time may be described as 'embodied' as it is defined by the activities and people involved, rather than by the number of minutes that pass (Davies 1994). The embodied experience of the duration of an event depends upon an awareness of the flow of time and also of the present moment (Valtteri and Dan 2014), consciously living in the present and appreciating every opportunity of daily life (Lovgren, Hamberg and Tishelman 2010).

Pemberton and Cox (2014) showed that people with chronic disease perceived time to go past quickly when they felt well, but when they felt ill they perceived time slowing down, prolonging the feelings of confinement and restriction (Pemberton and Cox 2014). Davies called this phenomenon "process time" which she described as "an enmeshing of time in social relations" (Davies 1996, p. 583). The length of time an activity takes is not predicted by hours and minutes but by the nature of the task and the ability of the people involved.

Chronic illness changes a person's perspective on the experience of time. A study by Zhou, 2010 into the experiences of people with HIV/AIDS in China showed that the constraints of the disease caused participants to gain a new perspective on their remaining days of life (Zhou 2010). Rasmussen and Elverdam's 2007 study of people who had survived cancer showed that a diagnosis of cancer resulted in a heightened awareness of the passing of time passing and a re-ordering of priorities based on valued relationships and activities (Rasmussen and Elverdam 2007). Bennett et al. (2013) found that people re-evaluated their use of time after receiving a diagnosis of ESKD (Bennett et al. 2013). People valued their relationships with others more highly than before, and had a greater appreciation for time spent together. In Kieran's (2005) narrative account of people living with kidney disease in Ireland she says, "Dialysis magnifies time. Time simply stands still as the patient, attached to a machine, unable to concentrate, read or work, simply endures" (Kierans 2005, p. 351)(Kierans 2005). People waiting for a kidney transplant develop an "awareness that time is running out" (Yngman et al. 2015, p. 4). Time that was not spent on dialysis was precious and the use of it was budgeted carefully. People waiting for a transplant experience an altered awareness of time, with months and years appearing to slow down while they wait, and which becomes harder as time goes by (Brown et al. 2006; Yngman-Uhlin, Fogelberg and Uhlin 2015).

3.5.3 Liminality

Liminality has been described as "the space betwixt and between" (Sabo 2014, p.184), a dynamic transitional phase in between the moment when an experience has begun and the end point when the experience is complete (Sabo 2014; Turner 1977). Liminality has also been described as a process, starting with a sense of uncertainty and moving into a lasting phase of creating and recreating meaning within the experience of illness (Little et al. 1998). Kelly (2008) suggested that people in the in-between liminal states are also "between social roles, cultural expectations and status" (Kelly 2008, p. 336). She offers the concept of "living loss" as a theory to describe the active experience of living in a state of

liminality (Kelly 2008). In a study of 100 people with CKD, Molzahn et al. reported the liminal spaces in this group as: "Living/Not Living", "(In)Dependence", "Restrictions/Freedom", "Not Normal/Normal", "Worse Off/Better Off" and "Alone/Connected" (Molzahn et al. 2008, p. 16-18). The experience of living with CKD exists in a liminal space – not fully identifying with the sick role, but neither being really well (Molzahn, Bruce and Sheilds 2008). Bruce et al. reported the experiences of liminality of people with HIV/AIDS, CKD and cancer. Participants experienced opposing feelings: being ill but not being ill; fearful but fearless; alive but not living; existing in the overlapping space. They hid their illness from others, living with uncertainty and finding it hard to make plans (Bruce et al. 2014). Waiting for a transplant has been described as "until transplant … and after transplant" (Brown 2006, p. 130) and a liminal space "between the roles of sick and healthy" (Crowley-Matoka 2005, p. 821) that becomes a way of life for people while they wait (Crowley-Matoka 2005). People understand there is nothing they can do that would affect when the call will come and yet they have to remain on high alert in the present moment (Pierce 2014) living in both a constant state of preparedness with phone charged and bag packed, while taking one day at a time and trying not to think about the long wait ahead (Yngman-Uhlin, Fogelberg and Uhlin 2015).

These concepts of time are all relevant to the experience of waiting for a kidney transplant. Renal registries calculate maximum, minimum and median waiting times and present them in clock time (Barbour 2009). However the actual experience of living on dialysis while waiting on the list is a liminal experience; ready and prepared for a transplant, but not transplanted yet (Brown et al. 2006). The length of the wait in embodied time involves dialysis and all the physical effects of ESKD, and cannot be predicted by the clock (Moran, Scott and Darbyshire 2011; Yngman-Uhlin, Fogelberg and Uhlin 2015). The experience of time is reconstructed, focussing on day to day life and re-evaluating the importance of relationships and activities (Bennett et al. 2013).

3.6 Uncertainty

Uncertainty occurs when a person cannot make sense of the situation they find themselves in due to lack of familiarity with what is happening or because the inability to predict what will happen in the end (Weitz 1989). The concept of uncertainty has been studied over many years and various definitions have been suggested (Mast 1995). Uncertainty has been defined as a perceptual state that changes over time (Hilton 1992); as a "complex cognitive stressor" (Mast 1995, p. 4) ; as "… the inability to determine the meaning of

illness-related events … [or] … to accurately predict outcomes because sufficient cues are lacking" (Mishel 1990, p. 256); and as "... a perception of being unable to assign probabilities for outcomes that prompts a discomforting, uneasy sensation…" (Penrod 2001, p. 241). Uncertain situations may be ambiguous, inconsistent, vague, unpredictable, unfamiliar and lacking in information (McCormick 2002). The level of uncertainty is affected by the perceived levels of confidence and control a person has, with greater confidence and control being associated with reduced levels of uncertainty (Penrod 2007). By adopting appropriate coping strategies people may learn to adapt to the uncertain situation (Mishel 1988) and where uncertainty continues over a long period of time, the position of uncertainty itself becomes the new baseline from which the person moves forward and adapts (Mishel 1990).

The experience of waiting for a transplant is uncertain, based as it is on the death of a compatible donor at a point in the future which is unknown and unpredictable (Tong et al. 2015). While the thought of getting a transplant gives people hope (Bjork and Naden 2008; Brown et al. 2006; Jonsén, Athlin and Suhr 2000; Moran, Scott and Darbyshire 2011; Pierce 2014; Yngman-Uhlin, Fogelberg and Uhlin 2015), as time goes by hope changes to uncertainty (Moran, Scott and Darbyshire 2011; Pierce 2014). Waiting for a transplant has been described as described as an "emotional rollercoaster" with uncertainty the "only constant in this state of flux" (Pierce 2014, p. 104). Martin et al. (2010) looked at the causes of uncertainty both before and after transplantation. They found that medical sources of uncertainty for people included trying to make complicated decisions with inadequate information, including the problem of not knowing when an organ would become available. Personal and social uncertainty were caused by a lack of clarity surrounding their role and identity (Martin et al. 2010). Pelletier investigated whether people waiting for a kidney transplant do indeed 'grow through uncertainty' as Mishel proposes (Pelletier 2012). Her quantitative study used numeric scales to measure uncertainty and growth through uncertainty in 103 people who were waiting for a kidney transplant in the US. The results showed a clear relationship between the length of time spent waiting and the amount of growth through uncertainty, thus supporting Mishel's theory (Mishel 1990). The study also showed that uncertainty increases as waiting time goes on (Pelletier 2012).

Waiting for a transplant includes the experience of living with a chronic illness which itself is a source of uncertainty. The study by Bjork and Naden (2008) into the experience of

waiting for a liver transplant found that people experienced uncertainty related to both the fear of dying before they received a transplant and the effect of their disease on everyday life while they waited (Bjork and Naden 2008). Lasker et al. (2010) found that uncertainty in people waiting for a liver transplant was related in part to the fatigue of living with end stage liver disease, as well as depression, fear and anxiety (Lasker et al. 2010). In her auto-ethnographic account of living with ulcerative colitis Moore (2013) concludes that "… chronic illnesses are unpredictable; living with them fills the mind with uncertainty" (Moore 2013, p. 206-7). The uncertainty of chronic illness can be related to finding a diagnosis or an effective treatment option (Stewart and Sullivan 1982). The person may experience doubts about their future prospects for recovery or for ongoing life with a chronic illness (Bjork and Naden 2008; Bury and Wood 1979).

Uncertainty also features as a theme in the literature regarding the experience of waiting. People living with cancer or waiting for surgery at an unspecified time live with an uncertain future (Hajdarevic, Rasmussen and Hörnsten 2014; Johnson, Horwood and Gooberman-Hill 2014). Stating that "waiting is often more anxiety-provoking than even dire medical procedures and diagnoses" (Sweeny 2012, p.259), Sweeny points out the link between waiting, uncertainty and anxiety, a phenomenon called rumination, where people faced with waiting for an uncertain outcome have repetitive and unrelenting thoughts (Sweeny 2012). Turning over the possible outcomes in their minds, rumination can result in increased anxiety. Uncertainty is a source of impatience and agony to people while they wait for a transplant (Jonsén, Athlin and Suhr 2000).

People waiting for a kidney transplant live with uncertainty that may be related to living with a chronic illness, to waiting itself or to the uncertain outcome of the transplant. As the symptoms and situations of illness that once caused uncertainty become familiar, they eventually become part of the normal routine and people adjust to living with uncertainty (Pelletier 2012).

3.7 Strategies for managing the waiting period

People have inherently different levels of tolerance for waiting (Sweeny and Andrews 2014) with those who are more naturally optimistic describing less anxiety than people with a more pessimistic outlook. While a coping style is a characteristic within a person (Sweeny and Andrews 2014), other factors have been identified that affect the way people manage the waiting period for a transplant. These are emotional regulation; the provision of information about transplantation; and social support provided by family, friends and other

non-medical people. These factors have been found to be effective in reducing uncertainty while people wait for a transplant (Cupples et al. 1998; Kimmel 2001; King, Dan and Johnstone 2006; Naef and Bournes 2009; Rodrigue and Baz 2007; Stone et al. 2013; Weems and Patterson 1989).

3.7.1 Emotional regulation

"Emotional regulation" (Sweeny and Cavanaugh 2012, p.153), involves dealing with uncertainty by not thinking about it – denying that the problem exists or using distraction to lessen the impact of the uncertainty(Brown et al. 2006). People prepare themselves for a bad outcome by moderating their hopes for the future or by re-evaluating the significance of the outcome so that bad news is received as less important (Brown et al. 2006). They may also prepare themselves practically and emotionally for a negative outcome, thereby reducing the disruption of bad news and giving the feeling of being in control while they wait (Sweeny and Cavanaugh 2012). Distraction is another form of emotional regulation that has been found to be helpful in the context of waiting for a transplant (Naef and Bournes 2009). Keeping busy with activity occupies the mind and diverts attention from the outcome of the wait.

3.7.2 Providing information

Communication and information are essential to resilience for individuals waiting for organ transplant (Pierce 2014; Yorke and Cameron-Traub 2008). Facts communicated by the healthcare providers and found on the internet serve to relieve anxiety, while lack of information increases the frustration of waiting for a transplant (Yngman-Uhlin, Fogelberg and Uhlin 2015) and causes people to feel forgotten, afraid and insecure (Jonsén, Athlin and Suhr 2000). Where unforeseen delays unexpectedly extend the length of a wait, negative feelings of anxiety can be eased by providing people with information (Cheng and Tsai 2014; Guenter, Hetty van Emmerik and Schreurs 2014). Information reduces the level of uncertainty in the situation and gives people a greater sense of being in control (Sweeny 2012).

People living with a chronic disease seek to validate and understand their experience by learning about their condition (Bury 1991; Stewart and Sullivan 1982). The communication of information results in people on the transplant waiting list feeling better cared for and supported (Rodrigue, Mandelbrot and Pavlakis 2011; Yngman-Uhlin, Fogelberg and Uhlin 2015). People combine medical information with personal stories to create their own

narrative of the experience. Bury suggested that part of the purpose for creating these narratives is legitimation of their chronic condition; to understand how their sense of self has been altered by the disease and to gain perspective (Brown et al. 2006; Bury 1991). As the everyday life is disrupted by chronic illness, so the individual seeks knowledge from new sources, both informal and professional, in order to contextualise (Stephens, McKenzie and Jordens 2014) and to make sense of their experience (Bury and Wood 1979; Michael 1996). Studies have repeatedly found that people who are waiting for a transplant require the communication of regular information to help them cope with the uncertainty of waiting while living with a chronic illness (Jonsén, Athlin and Suhr 2000; Yngman-Uhlin, Fogelberg and Uhlin 2015; Yorke and Cameron-Traub 2008).

In a study investigating the use of information to manage uncertainty in people awaiting organ transplantation, Stone et al. (2013) listed a range of sources that people used to increase their knowledge. These included the internet, books, conferences and seminars, their medical team and other people who were either waiting for a transplant or had experienced a transplant. The study found that people preferred to receive information from other people rather that printed material or the internet and they valued information from peers more highly than their doctors as they had been through the experience themselves (Stone et al. 2013). In a study of people with cancer, participants found the greatest encouragement in other people with cancer who they met at a support group (Mulcahy, Parry and Glover 2010). The support group provided an alternative source of information that was both comforting and empowering and which delivered education and practical evidence of how to live with a disease far better than a doctor or a description on the internet.

Although many participants cited information as a useful way of managing uncertainty, a number recognised that certain types of information actually increased their anxiety (Stone et al. 2013). Some participants chose to avoid information about negative outcomes as an active way of dealing with their uncertainty.

A number of studies have documented the use of formal educational support for people awaiting kidney transplant. Weems, Taylor and Davidson (1983) developed a programme that involved sending six monthly letters to people who were on the waiting list for a kidney transplant. The letters covered topics relating to the post-transplant period such as medications, diet and exercise, emotional challenges and potential complications (Weems and Patterson 1989). Participants in the study reported that as well as giving helpful

information to them and their families, the letters also made them feel cared for by the medical team. A study by King, Dan and Johnstone (2006) used a series of four weekly classes for people on the transplant waiting list run by the nephrology social workers (King, Dan and Johnstone 2006). At the third class in the series transplant recipients came to share their first hand experiences and the study reports that it was at this point that participants developed a deeper understanding of the benefits and pitfalls of the transplant process. A study by Rodrigue, Mandelbrot and Pavlakis (2011) tested whether support in the form of either; one to one therapy individually tailored to the participant's QOL needs; structured emotional and educational support; or standard care of clinic visits alone had any measureable effect in improving QOL and reducing psychological distress in people waiting for a kidney transplant (Rodrigue, Mandelbrot and Pavlakis 2011). The one to one therapy showed the greatest effect in improving QOL, but there was no difference between the one to one therapy and the supportive therapy in reducing psychological distress. Both interventions were better than standard clinic visits alone.

These studies show that the communication of information is helpful to people who are waiting for a transplant, although certain types of negative information may add to a person's anxiety (Stone et al. 2013). Information should be provided in a format that meets people's individual needs, but it seems that it is most powerful when it comes from others who have been through the experience themselves (Calestani et al. 2014; King, Dan and Johnstone 2006; Stone et al. 2013).

3.7.3 Support from others

Social support has been acknowledged as a factor in a person's adjustment to a diagnosis of chronic illness (Kimmel 2001) and comes from sources such as family members, friends, workmates, other people with the same condition, spiritual leaders, medical teams and online support groups (Bury and Wood 1979; Godbold 2013; Kimmel 2001). Chronic disease gives people a fresh appreciation of the support they receive from those around them (Sheilds et al. 2015). Bennett et al. (2013) found that that living on dialysis with ESKD made people more aware of the importance of relationships, with some participants citing seeing their children or grandchildren grow up as the reason for carrying on with dialysis (Bennett et al. 2013). People described the gratitude they feel towards family members who support them (Monaro, Stewart and Gullick 2014; Polaschek 2000; Tong et al. 2009). As 'care givers' adapt to becoming 'cared for', the success of such reframed relationships

rests upon the dynamics that existed prior to the chronic disease diagnosis (Monaro, Stewart and Gullick 2014).

In the context of waiting for a transplant, good social support has been shown to contribute towards better coping effectiveness (Jalowiec, Grady and White-Williams 2007; Tong et al. 2015). Study participants appreciate being listened to and consistently report their need for supportive relationships and information about the transplant process (Brown et al. 2006; Jonsén, Athlin and Suhr 2000; Pierce 2014; Yngman-Uhlin, Fogelberg and Uhlin 2015; Yorke and Cameron-Traub 2008). Scott et al. (2011) recommended the use of social relationships as a means of helping people to manage their feelings of uncertainty before and after transplantation (Scott et al. 2011). By observing how others live with dialysis and transplantation, a sense of normality is created around an experience that is not common in the general population.

Relationships with the healthcare team have been found to be an important source of support for people waiting for a transplant (Brown et al. 2006; Yngman-Uhlin, Fogelberg and Uhlin 2015; Yorke and Cameron-Traub 2008). Regular communication with the medical team helped people to feel less anxious while they waited (Yngman-Uhlin, Fogelberg and Uhlin 2015), while contact with the nurses was described as an essential care need and provided reassurance that participants had not been forgotten while they waited (Yorke and Cameron-Traub 2008). Some people felt isolated and wished for better support from the healthcare team while they waited (Brown et al. 2006; Jonsén, Athlin and Suhr 2000). In a study from 1996 of 16 people with various types of chronic conditions, people reported feeling unseen by their doctors and viewed only as a disease, without being given time to make a proper human connection (Michael 1996). Where information from the medical team was felt to be lacking people tended to feel forgotten and frustrated (Brown et al. 2006; Jonsén, Athlin and Suhr 2000; Yngman-Uhlin, Fogelberg and Uhlin 2015; Yorke and Cameron-Traub 2008). Lack of information from healthcare providers caused people to seek out information for themselves from sources such as the internet, other patients and their own observations (Godbold 2013; Wehrens 2014). Relationships with doctors and other healthcare providers changed as the person became the expert based on their experiential knowledge of their own chronic condition (Wehrens 2014).

As well as needing and receiving support from others while waiting for a transplant, people fear that they are being a burden to their loved ones (Cupples et al. 1998; Yngman-Uhlin,

Fogelberg and Uhlin 2015). A study into the experience of people whose spouses were waiting for a lung transplant found that spouses demonstrated clinically low QOL scores and caregiver strain (Rodrigue and Baz 2007). Despite being thankful for the support they received, people with CKD worried that they were being a burden to their loved ones by being dependent upon their help and assistance while they waited for a kidney transplant (Monaro, Stewart and Gullick 2014; Polaschek 2003a). In order to protect their support network from being burdened, people sometimes chose to hold back information about their illness and how they were feeling (Öhman, Söderberg and Lundman 2003; Tong et al. 2009).

The importance of feeling supported by a community of people is a commonly recurring finding in the literature abut chronic illness (Kimmel 2001), uncertainty (Scott et al. 2011) and waiting for a transplant (Naef and Bournes 2009). People need interaction with others and the opportunity to give and receive information (King, Dan and Johnstone 2006; Yngman-Uhlin, Fogelberg and Uhlin 2015; Yorke and Cameron-Traub 2008). Effective social support helps people to endure the wait for a transplant (Jalowiec, Grady and White-Williams 2007).

3.8 Conclusion

This literature review has described a wide range of literature that is relevant to help understand the experience of waiting for a kidney transplant from a deceased donor. People move from an initial perception of their CKD as a temporary interruption (Charmaz 1991), to waiting many years with a chronic illness (Pierce 2014). Uncertainty is a common feature of living with a chronic illness (Sheilds et al. 2015), waiting (Johnson, Horwood and Gooberman-Hill 2014) and waiting for a transplant (Moran, Scott and Darbyshire 2011), and it increases as the wait for the transplant goes on (Corruble et al. 2010; Silva et al. 2014), resulting in greater anxiety and a poorer QOL (Lin et al. 2010). The uncertainty of waiting for a transplant results in people feeling that their lives are on hold (Bjork and Naden 2008; Brown et al. 2006; Moran, Scott and Darbyshire 2011; Pierce 2014). Time becomes embodied with the wait for a transplant not measured in minutes and hours but taking as long as it takes (Kierans 2005). Living in a liminal state, ready for transplant but not yet receiving it (Brown et al. 2006), causes people to reconstruct their use of time, prioritising the relationships and activities that are the most meaningful to them (Bennett et al. 2013; Yngman-Uhlin, Fogelberg and Uhlin 2015). Relationships are highly valued as a source of emotional support while people wait (Rodrigue, Mandelbrot and Pavlakis 2011;

Yngman-Uhlin, Fogelberg and Uhlin 2015) as is the acquisition of knowledge (Stone et al. 2013).

The next chapter will present a systematic review of the literature relating specifically to the experience of waiting for a kidney transplant.

CHAPTER 4 **SYSTEMATIC REVIEW OF QUALITATIVE DATA**

4.1 Introduction

This chapter reports a systematic review of the qualitative literature related to the experience of waiting for a kidney transplant from a deceased donor. It describes the process of conducting a systematic review including the design of a protocol; the development of a search strategy; critical appraisal and data extraction. Findings of all included studies were be synthesised to provide a meta-synthesis of the evidence. The systematic review has been published in the JBI Database of Systematic Reviews and Implementation Reports (Burns, Fernandez and Stephens 2015)

4.2 Why a systematic review?

Systematic review methodology has been described as "… a protocol driven and quality focused approach to summarising healthcare evidence" (Bearman et al. 2012, p. 625). The concept of systematically evaluating care through controlled trials was first advocated by Archie Cochrane in his 1972 seminar, and later book of the same name, 'Effectiveness and efficiency: Random reflections on health services' (Cochrane 1972). He proposed combining the evidence of multiple controlled trials to form a critical summary (Starr et al. 2009) and expounded the importance of calibrating survey instruments, and of identifying and measuring any sort of bias in a study (White 1997). Based on his proposition, the Cochrane Collaboration was established in Britain in 1993 and is now an international organisation with contributors from over 100 countries. The Cochrane Collaboration provides evidence for health care practice through an online repository of systematic reviews of randomised controlled trials that is accessible worldwide known as the Cochrane Library (*The Cochrane Collaboration History* 2013). While the Cochrane Collaboration is concerned with processing quantitative evidence from randomised controlled trials, other forms of evidence are equally useful for informing care and methods for the critical appraisal and synthesis of qualitative research, economic analysis and expert opinion have been developed (*Joanna Briggs Institute, Systematic Review* 2013). The Joanna Briggs Institute (JBI) was established in 1997 and provides another online source of systematic reviews including research from the fields of nursing, allied health, and management as well as medicine in the Joanna Briggs Institute Database of Systematic Reviews and Implementation Reports (*Joanna Briggs Institute - About Us* 2012).

The process of writing a systematic review begins with the development of a detailed protocol to review the evidence on a given topic (Bearman et al. 2012). Systematic reviews are considered to be the highest level of evidence because of the rigorous process involved for their development. The first step of the process involves developing the review question, including inclusion and exclusion criteria to clearly define parameters around the question under investigation. A search strategy is constructed and a comprehensive search of published and unpublished data is made. Once appropriate literature is identified, each article is appraised for its relevance to the question and for the quality of its data by two independent reviewers using standardised appraisal tools. The use of two reviewers using the same appraisal tools is a strength of the systematic review methodology as it is effective in limiting bias. The final step is for the appraised data to be combined and summarised into a meta-synthesis of all the findings (*Joanna Briggs Institute, Systematic Review* 2013).

The systematic review described in this chapter has been carried out using the Joanna Briggs Institute Qualitative Assessment and Review Instruments (JBI-QARI) for appraisal and data extraction and has been published in the JBI Database of Systematic Reviews and Implementation Reports (Burns, Fernandez and Stephens 2015). Prior to commencement of this review a search was performed through the JBI Database of Systematic Reviews and Implementation Reports, the Cochrane Library, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medical Literature Analysis and Retrieval System Online (MEDLINE) and the database of the American Psychological Association (PsycINFO) to ensure that no similar systematic reviews had previously been published.

The reason for including a systematic review in this master's thesis is to provide a detailed appraisal of the evidence relating specifically to the experience of waiting for a kidney transplant from a deceased donor. In the previous chapter literature relating to a wide range of topics was presented, to provide a comprehensive foundation for the forthcoming study. This is complemented by the systematic review in which a narrowly defined section of the literature will be closely examined. The combination of the general literature review and the systematic review gives an extensive insight into the experience on which to base the study data collection and analysis.

4.3 Objectives of this systematic review

Preliminary searches revealed that while some primary qualitative research had been conducted, these studies had not been systematically reviewed. The purpose of this review

was to synthesise qualitative evidence relating to the experiences of people who were living on dialysis while waiting for a kidney transplant from a deceased donor,

4.4 Inclusion criteria for studies in the systematic review

4.4.1 Types of participants

This review considered studies that included adult patients who were aged 18 years and over when they started dialysis, in order to examine the experiences of adults rather than children or adolescents. It only considered studies including people who were waiting for a kidney transplant from a deceased donor and who had been on dialysis (either haemodialysis or peritoneal dialysis) for up to 15 years. The advent of erythropoietin in the mid-1980s combatted the effects of anaemia associated with ESKD and considerably improved the QOL of people on dialysis (Cotton and Holechek 1989; Rutherford 1991). Around the same time advances in immunosuppressive medication meant that transplantation became a feasible option with good outcomes for more people (Danovitch 2010a). Therefore this systematic review only includes studies of people who had been on dialysis for up to 15 years, because people who were on dialysis for longer may have had experiences that are not typical today. This review did not consider people receiving dialysis for acute kidney failure, people who were waiting for a transplant from a living donor or people waiting for a pre-emptive transplant from a deceased donor.

4.4.2 Phenomena of interest

This review considered studies that investigated the experiences of adults who are waiting for a kidney transplant from a deceased donor including the impact that waiting for a transplant had on lifestyle and day-to-day living.

4.4.3 Context

This systematic review considered studies involving adults with ESKD who were on either haemodialysis in a hospital or a satellite unit or at home, or on peritoneal dialysis, and who were waiting for a kidney transplant from a deceased donor.

4.4.4 Types of studies

This review considered studies that focused on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research and feminist research. Qualitative research is employed to investigate questions relating to a person's experiences (Denzin and Lincoln 2011). As this review is concerned with the

person's experience of waiting for a kidney transplant it is appropriate to make a review of qualitative studies.

4.4.5 Search strategy

The search strategy aimed to find both published and unpublished studies. A three-step search strategy was employed in this review. An initial limited search of MEDLINE and the Excerpta Medica Database (Embase) was undertaken followed by an analysis of the text words contained in the title and abstract, and of the index terms used to describe articles. A second search using all identified keywords and index terms was undertaken across all included databases. The titles and abstracts of studies identified in this search were scrutinised and full text obtained to ascertain whether they met the inclusion criteria. Thirdly, the reference lists of all identified reports and articles were searched for additional studies. Only studies published in English were considered for inclusion in this review. Studies published from 1985 to 2013 were considered for inclusion, which reflected the advances in dialysis and transplantation previously mentioned.

The databases searched included:

CINAHL (1985 – 2013)

MEDLINE (1985 – 2013)

Embase (1985 – 2013)

Cochrane Database of Systematic Reviews

PsycINFO (Ovid)

The search for unpublished studies included:

ProQuest Dissertations and Theses

OpenGrey

Virginia Henderson International Nursing Library

New York Academy of Medicine

The initial keywords used were: kidney/renal failure, kidney/renal transplant, quality of life, experiences, not living donors, waiting, qualitative, dialysis. The literature search was carried out in consultation with a librarian at the University of Wollongong. Separate search strategies were carried out for each database and references were entered into

Endnote. All duplicate references were removed. A detailed search strategy has been reported in Appendix 2.

4.5 Method of the review

Papers identified in the searches were selected for inclusion in the study if they met the inclusion criteria. That is, they included adult patients aged 18 years and over when they started dialysis, who were waiting for a kidney transplant from a deceased donor and who had been on dialysis for up to 15 years.

4.5.1 Assessment of methodological quality

Papers were read in full and assessed for methodological validity by two independent reviewers using the JBI-QARI appraisal instrument (Appendix 3) prior to their inclusion in the review. No disagreements between the reviewers occurred and therefore the involvement of a third reviewer was not required. In order to include only high quality studies, a cut off value of Mean minus one Standard Deviation was used (Jakobsen et al. 2014).

4.5.2 Data collection

Data was extracted from papers by two independent reviewers using the JBI-QARI standardised data extraction tool (Appendix 4). The use of two reviewers and standardised data extraction tools minimises error and creates a consistent data set that can then be used for subsequent synthesis (Munn, Tufanaru and Aromataris 2014). The data extracted included specific details about the phenomena of interest, populations, study methods and outcomes relating to waiting for a kidney transplant. If participants in the study included both those waiting and those not waiting for a transplant, only findings that specifically related to waiting for a transplant were extracted. The level of credibility of the findings was deemed to be 'unequivocal' where the finding was supported either by reference to comments made by the participants of by the use of direct quotations of the participant's words. Where the finding was made without reference to words spoken by the participants, but with logical progression from other findings and comments the finding was deemed 'credible'.

4.5.3 Data synthesis

Qualitative research findings were pooled using JBI-QARI software. Findings were aggregated to generate a set of statements by assembling the findings according to their quality, and categorising them on the basis of similarity in meaning. These categories were

then subjected to a meta-synthesis in order to produce a single comprehensive set of synthesised findings that can be used as a basis for evidence-based practice.

4.6 Systematic review results

4.6.1 Search results

Eight hundred and eighty seven studies were identified from the search strategy and 17 from other sources. Following removal of 33 duplicates the majority of the remaining papers were excluded based on a review of the title and abstract against the inclusion criteria. A total of 16 studies were deemed potentially eligible for the review and full text of these studies was obtained. The 16 studies were critically appraised for methodological quality using the JBI QARI critical appraisal checklist for interpretive and critical research (Appendix 3). Based on the JBI-QARI assessment of methodological quality, the calculated mean quality score was 16.88 (SD 2.28) (Table 3), therefore the quality threshold score was calculated to be 14.6. Two studies with scores below the quality threshold were excluded (Murray, Conrad and Zarifian 1999; Wells 2009). A further two papers were excluded as two of the studies resulted in the publication of two papers each, (Moran, Scott and Darbyshire 2011; Polaschek 2003b) therefore only one paper for each study was included. This left a total of 12 studies included in the review. The search process for the review is included below in Figure 8 and the critical appraisal scores are recorded in Table 3.

In the two studies where all the participants were waiting for a transplant (Calvey and Mee 2011; Polaschek 2000) there was a total of 18 findings of which 14 were 'unequivocal' and four were 'credible'. In the other ten studies where the participants included both people waiting and not waiting for a kidney transplant (Dekkers, Uerz and Wils 2005; Hagren et al. 2001; Herlin and Wann-Hansson 2010; Kaba et al. 2007; Landreneau and Ward-Smith 2007; Moran 2008; Rittman et al. 1993; Sadala et al. 2012; Shih and Honey 2011; Yu and Petrini 2010) a total of 15 findings were found relating to waiting for a transplant. One of these was a 'credible' finding while the other 14 were 'unequivocal'. This gave a total of 33 study findings to be included in the review.

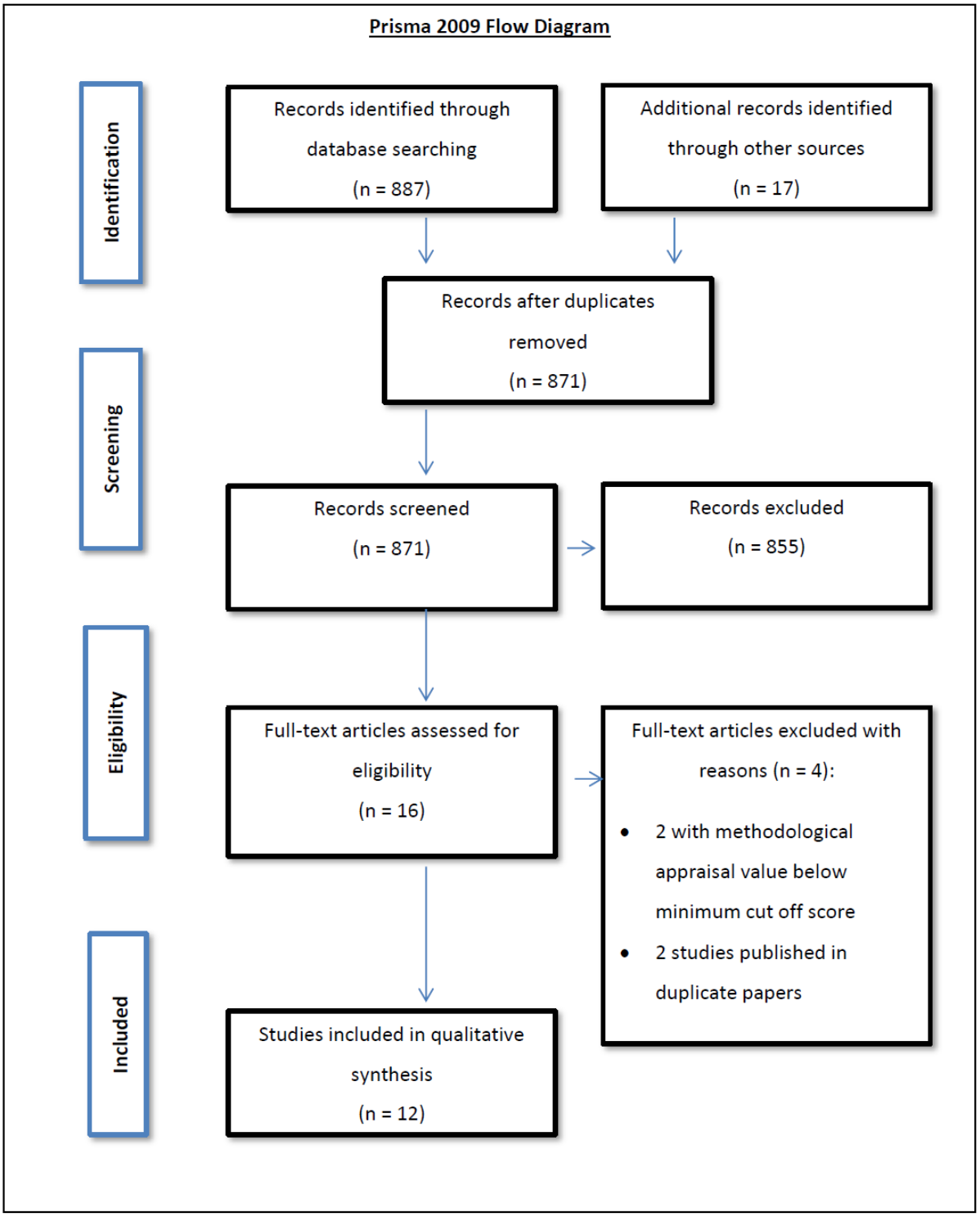

Figure 8: Screening and selection process flow diagram

Table 3: Critical appraisal scores

JBI critical appraisal checklist for interpretive and critical research											
Citation	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	**Overall Appraisal Value**
Included studies											
Calvey D, Mee L., 2011	2	2	2	2	2	0	1	2	2	2	17
Dekkers W, Uerz I, Wils J-P., 2005	2	2	2	2	2	2	1	2	1	2	18
Hagren B, Pettersen I, Severinsson E, Lützén K, Clyne N., 2001	2	2	2	2	2	1	1	2	2	2	18
Herlin C, Wann-Hansson C., 2010	2	2	2	2	2	1	2	2	2	2	19
Kaba E, Bellou P, Iordanou P, Andrea S, Kyritsi E, Gerogianni G, et al., 2007	2	2	2	2	2	0	0	2	2	2	16
Landreneau KJ, Ward-Smith P., 2007	2	2	2	2	2	0	2	2	2	2	18
Moran A.,2008	2	2	2	2	2	2	2	2	2	2	20
Polaschek N., 2000	2	2	2	2	2	2	2	2	2	2	20
Rittman M, Northsea C, Hausauer N, Green C.,1993	2	2	2	2	2	0	1	2	1	2	16
Sadala MLA, Bruzos GAdS, Pereira ER, Bucuvic EM., 2012	2	2	2	2	2	0	0	2	2	2	16
Shih LC, Honey M., 2011	1	2	2	2	2	0	0	2	2	2	15
Yu H, Petrini MA., 2010	1	2	2	2	2	2	0	2	2	2	17
Excluded studies											
Murray LR, Conrad NE, Zarifian A., 1999	0	2	2	2	2	0	0	2	1	2	13
Wells SA., 2009	1	2	2	1	1	0	0	2	2	1	12
Moran A, Scott A, Darbyshire P., 2011	2	2	2	2	2	1	2	2	2	2	19
Polaschek N., 2003	2	2	2	2	2	0	0	2	2	2	16
	Where “Yes” = 2, “No” = 0 and “Unclear” = 1										

4.6.2 Description of included studies

The 12 studies included in this review used varying qualitative designs. Seven studies adopted a phenomenological methodology (Calvey and Mee 2011; Herlin and Wann-Hansson 2010; Landreneau and Ward-Smith 2007; Moran 2008; Rittman et al. 1993; Sadala et al. 2012; Yu and Petrini 2010), three were described as interpretive without specifying a methodology (Hagren et al. 2001; Polaschek 2000; Shih and Honey 2011), one used grounded theory (Kaba et al. 2007) and one virtue ethics (Dekkers, Uerz and Wils 2005). Two of the studies were theses (Moran 2008; Polaschek 2000)and 10 were published papers (Calvey and Mee 2011; Dekkers, Uerz and Wils 2005; Hagren et al. 2001; Herlin and Wann-Hansson 2010; Kaba et al. 2007; Landreneau, Lee and Landreneau 2010; Rittman et al. 1993; Sadala et al. 2012; Shih and Honey 2011; Yu and Petrini 2010).

All the studies used interviews as the method of data collection. Data collection took place in the dialysis unit in seven studies (Calvey and Mee 2011; Hagren et al. 2001; Herlin and Wann-Hansson 2010; Kaba et al. 2007; Moran 2008; Rittman et al. 1993; Yu and Petrini 2010), and in the participant's home in three (Dekkers, Uerz and Wils 2005; Polaschek 2000; Sadala et al. 2012). Two of the studies (Landreneau and Ward-Smith 2007; Shih and Honey 2011) did not report where data collection took place. Data analysis methods included Colaizzi's (Colaizzi 1978) seven step framework for phenomenological analysis (Calvey and Mee 2011; Landreneau and Ward-Smith 2007; Yu and Petrini 2010), Diekelmann, Allen and Tanner's (Diekelmann, Allen and Tanner 1989) seven stage hermeneutical analysis process (Moran 2008; Rittman et al. 1993; Shih and Honey 2011), interpretative phenomenological analysis (Dekkers, Uerz and Wils 2005), interpretive content analysis (Hagren et al. 2001), Ricour's (Ricoeur 1984) three stage hermeneutic method (Sadala et al. 2012), McKracken's (McCracken 1988) analytic categorization (Polaschek 2000), Giorgi's (Giorgi 1997) descriptive phenomenological method (Herlin and Wann-Hansson 2010) and theoretical sampling (Kaba et al. 2007).

The number of participants ranged from six (Polaschek 2000) to 23 (Kaba et al. 2007) with a total of 151 participants in all 12 studies. Participant ages ranged between 20 to 82 years (Calvey and Mee 2011; Dekkers, Uerz and Wils 2005; Hagren et al. 2001; Herlin and Wann-Hansson 2010; Kaba et al. 2007; Landreneau and Ward-Smith 2007; Moran 2008; Polaschek 2000; Rittman et al. 1993; Sadala et al. 2012; Shih and Honey 2011; Yu and Petrini 2010). Of the 12 studies included in the review, two specifically stated that all the participants were waiting for a transplant. In the remaining 10 papers the participants included both

those waiting and those not waiting for a transplant. Therefore only findings that specifically related to waiting for a transplant were extracted from these 10 papers and included in the review. The characteristics of each study are described in Table 4.

Table 4: Summary of included studies

Study	Methodology	Methods	Participants	Phenomena of interest
Calvey and Mee, 2011	Phenomenology	In depth semi-structured interviews	7 HD patients who were waiting for a transplant chosen through purposive sampling (age 29-60). All participants were waiting for a kidney transplant	To step into the lives of HD patients once they step outside the dialysis unit
Dekkers, Uerz and Wils, 2005	Virtue ethics	In depth semi-structured interviews	7 people with end stage renal disease and on dialysis (ages 55-82). An unknown number of participants were waiting for a kidney transplant	What are the moral challenges faced by patients with an ESKD? Do patients with an ESKD implicitly or explicitly speak in terms of virtue, when they are invited to tell the story of their illness and asked how they cope with the challenges of their illnesses? Are there elements in the patient's stories that can be interpreted in terms of Aristotelian virtue ethics?
Hagren, et al. 2001	Qualitative interpretative	Semi-structured interviews	15 patients, at least 3 months on maintenance HD (<1year - >3 years), age range 50-79years. An unknown number of participants were waiting for a kidney transplant	Patient's experiences of suffering from ESKD

Herlin and Wann-Hansson, 2010	Phenomenology	Interviews	9 HD patients aged 30-44 years. Eight participants were waiting for a kidney transplant.	How HD patients between 30 and 45 years of age experienced their dependence on HD treatment
Kaba, et al. 2007	Grounded theory	Interviews	23 HD patients, average age 62, average length of treatment 5.7years. An unknown number of participants were waiting for a kidney transplant	To explore how Greek patients receiving long-term HD perceive their problems and to describe the impact of HD on these patients' lives
Landreneau and Ward-Smith, 2007	Phenomenological approach, exploratory descriptive	Interviews	20 randomly selected HD patients, age range 21-77, on dialysis from 1-5 years. An unknown number of participants were waiting for a kidney transplant	To explore what patients on HD perceive concerning choice among renal replacement therapies: transplantation, HD and PD
Moran, 2008	Hermeneutical phenomenology	Interviews	16 participants aged 31-66 years and on HD 10 months-5 years. At least 10 participants were waiting for a transplant.	Accurate, detailed and in-depth description of the person's experience of ESKD and HD therapy
Polaschek, 2000	Critical, interpretive	Interviews	Six Pakeha men living on home HD for more than one year and no longer than ten years aged from their late 20s-60s. All participants were waiting for a kidney transplant.	The concerns of Pakeha men living on home HD
Rittman et al. 1993	Heideggerian phenomenology	Interviews	6 dialysis patients aged 39-58 years, on dialysis 3-14 years (5 male, 1 female, 5	The meanings of living with chronic renal failure as described by patients and the related

			white, 1 black). An unknown number of participants were waiting for a kidney transplant.	nursing implications
Sadala et al. 2012	Phenomenology	Narrative interviews	19 participants aged 20-77, on PD for at least 6 months. An unknown number of participants were waiting for a kidney transplant.	The meaning of PD as experienced by patients with chronic renal failure
Shih and Honey, 2011	Qualitative, interpretive	Semi-structured interviews	Seven participants aged 46-77 years, on HD for 4-10 years. An unknown number of participants were waiting for a kidney transplant.	To explore the impact that dialysis has on Maori and their whanau/families
Yu and Petrini, 2010	Phenomenology	Semi-structured in-depth interviews	16 HD patients selected by purposive sampling, age 49-74 years, on dialysis for 3 months to 7 years. 6 participants were waiting for a kidney transplant.	To provide basic information concerning life experience and perceptions of ESKD in patients undergoing HD

4.7 Categorization and synthesis of qualitative research findings

From the 12 studies included in the review a total of 33 findings were extracted (Appendix 6) and aggregated to form 11 categories. From the 11 categories three synthesised findings (meta-syntheses) were derived as illustrated in Table 5 – QARI graph.

Table 5: QARI graph

Findings	Categories	Synthesised findings
Facing the world of renal failure and dialysis treatment (U)	Dependence and loss of control	Physical health and normal activities of living People who are waiting for a kidney transplant from a deceased donor are affected by the experience of living on dialysis with ESKD and its impact on their physical health and normal activities of living
The altered interrelationship of autonomy and dependence involved in living on dialysis: Dependence on the dialysis machine (U)		
The altered interrelationship of autonomy and dependence involved in living on dialysis: Their new healthcare relationships (U)		
The mortal, fragile self: facing their own mortality (C)	Mortality	
The mortal, fragile self: the issue of transplantation (U)		
Bodily self. Participants' descriptions of how they perceived themselves and the physical changes they had gone through (U)	Physical health	
Negotiating the requirements of dialysis to fit their lifestyle and the limitations involved (U)	Restricted life	
Total lack of freedom (U)		
Waiting for a kidney: Being on hold		

(U)		
Findings	**Categories**	**Synthesised findings**
Mental self. Participant's perceptions of themselves leading to feelings of powerlessness, worthlessness and low self-confidence. (C)	Character and state of mind	<u>Psychological health</u> The experience of waiting for a kidney transplant from a deceased donor impacts on a person's psychological wellbeing
Being on the waiting list for a kidney transplantation (C)	Hope	
Facing the world of renal failure and dialysis treatment (U)		
Future hopes (U)		
Gaining a sense of existential optimism (C)		
Gratitude – hope (U)		
Maintaining hope (U)		
The ongoingness and uncertainty of life on dialysis and the hope of a transplant: The expectation of a transplant (U)		
Waiting for a kidney: Living in hope (U)		
Choice (U)	Knowledge	
Knowledge (U)		
The growing/learning self (U)		
Functional self. The impact on what participants perceived to be their normal routines and their varying roles in life. (U)	Life losses	
Lost dreams. The loss of dreams introduced elements of sadness leading to anger and bitterness in the descriptions of perceived loss		

of planned future dreams (U)	Life losses (continued)	Psychological health (continued)
The ongoingness and uncertainty of life on dialysis and the hope of a transplant: Experiencing life on dialysis as ongoing (U)		
Psycho-social aspect: Anxiety (U)	Stress and anxiety	
Stress from HD (U)		
An Uncertain Future (U)	Uncertainty	
Being on the waiting list for a kidney transplantation (U)		
Gaining a sense of existential optimism (C)		
The ongoingness and uncertainty of life on dialysis and the hope of a transplant: Uncertainty about the future (U)		
Uncertainty (U)		
Waiting for a kidney: Uncertainty (U)		
Findings	**Categories**	**Synthesised findings**
Feelings of loneliness (U)	Relationships and community	Relationships and community People who are waiting for a kidney transplant place value on relationships and being part of a community. The experience of waiting for a kidney transplant from a deceased donor while living on dialysis with ESKD changes a person's relationships
Social self. The impact of HD on family and friends and the impact of family and friends on the lives of participants (U)		
The altered interrelationship The altered interrelationship of autonomy and dependence involved in living on dialysis: Changing personal relationships (U)		
The altered interrelationship of		

autonomy and dependence involved in living on dialysis: Their new healthcare relationships (U)		

4.7.1 Synthesised findings of the systematic review

Three synthesised findings were derived from the meta-synthesis of the study findings. Each synthesised finding is described below along with supporting illustrations from the literature and a full list of study findings is presented in Appendix 6. The approach adopted for meta-synthesis and presentation of the data is that of the Joanna Briggs Institute (Burns, Fernandez and Stephens 2015; Munn, Tufanaru and Aromataris 2014)

4.7.1.1 Synthesised finding 1: The physical experience of living on dialysis while waiting for a kidney transplant

People who are waiting for a kidney transplant from a deceased donor are affected by the experience of living on dialysis with ESKD and its impact on their physical health and normal activities of living. All of the studies referred to the impact that living on dialysis had on the participants' physical wellbeing including their normal lifestyle and activities of living. This meta-synthesis was created from four categories: 'physical health', 'mortality', 'dependence and loss of control', and 'restricted life' with a total of 10 findings.

Findings relating to physical health were reported in two studies (Calvey and Mee 2011; Polaschek 2000). The physical symptoms of ESKD and the effects of dialysis included general lack of energy, fatigue, an altered sleep pattern, itching and restless legs syndrome, hypotension, dizziness, loss of appetite, nausea, vomiting, anaemia, weakness, breathlessness and general malaise (Calvey and Mee 2011). Participants reported changes to their body image, particularly relating to the placement of the dialysis access and the symptoms of uraemia (Calvey and Mee 2011)

Following on from the theme of physical health was the concept of mortality. Two findings from one of the studies showed that participants comprehended their own mortality and their dependence on renal replacement therapy to maintain their lives (Calvey and Mee 2011). They were also aware that transplantation could only be achieved by the death of a donor and so what they were waiting and hoping for could only be brought about by the death of another (Calvey and Mee 2011).

Two of the studies contained three findings related to dependence and loss of control (Polaschek 2000; Sadala et al. 2012). Participants voiced their feelings of dependence upon people such as family, friends and hospital staff to cope with the dialysis regimen, and also

dependence on the dialysis machine in order to stay alive while they were waiting for a kidney transplant (Polaschek 2000). Loss of control is a concept that is similar to dependence. Participants reported experiencing loss of control in being unable to influence when a donor organ would become available for them (Sadala et al. 2012).

Three studies reported findings related to life on dialysis while waiting for a kidney transplant being a restricted life (Herlin and Wann-Hansson 2010; Moran 2008; Polaschek 2000). People felt that while they were waiting for a transplant that their life was 'on hold' (Moran 2008). They were unable to travel freely as they were restricted by the dialysis therapy (Herlin and Wann-Hansson 2010; Polaschek 2000) and they guarded the days in between dialysis sessions in order to have a 'normal' life (Polaschek 2000).

4.7.1.2 Synthesised finding 2: The psychological impact of waiting for a kidney transplant

The experience of waiting for a kidney transplant from a deceased donor impacts a person's psychological wellbeing. This meta-synthesis was created from six categories containing a total of 23 findings: hope, uncertainty, knowledge, life losses, stress and anxiety, and character and state of mind. Findings showed that the experience of waiting for a kidney transplant from a deceased donor had both a positive and negative effect on a person's psychological wellbeing.

The most commonly reported finding was that waiting for a kidney transplant gave people hope. Eight studies reported findings relating to hope (Calvey and Mee 2011; Dekkers, Uerz and Wils 2005; Hagren et al. 2001; Herlin and Wann-Hansson 2010; Moran 2008; Polaschek 2000; Rittman et al. 1993; Sadala et al. 2012). The expectation of getting a transplant one day helped people to cope better with the experience of living on dialysis while they waited. Findings showed that people believed their lives would return to normal after a transplant and that they would be able to resume all the normal activities that they could not do while they were waiting on dialysis.

Six studies reported findings about uncertainty (Calvey and Mee 2011; Hagren et al. 2001; Herlin and Wann-Hansson 2010; Kaba et al. 2007; Moran 2008; Polaschek 2000). It is not possible to predict when a donor kidney will become available, so people who were waiting for a kidney transplant experienced feelings of insecurity and doubt about whether the transplant would ever happen and whether everything would go well when it did occur.

Because the thought of getting a kidney transplant gives people hope, the uncertainty surrounding when it will happen causes people to experience stress and anxiety while they

wait. The two concepts are interrelated. Two studies reported findings about stress and anxiety (Shih and Honey 2011; Yu and Petrini 2010). If a kidney transplant was not valued so much, the ambiguity about timing would not have had such an impact on the people concerned.

Two studies reported three findings relating to knowledge (Calvey and Mee 2011; Landreneau and Ward-Smith 2007). When the person learned more about kidney disease, particularly the dialysis routine and kidney transplantation, they were able to cope better with the experience of waiting for a kidney transplant. Sources of knowledge mentioned were nephrologists, dialysis nurses and other dialysis patients (Landreneau and Ward-Smith 2007), although it was noted that information gained from other dialysis patients was often out of date and inaccurate.

Two studies reported three findings related to the concept of loss (Calvey and Mee 2011; Polaschek 2000). These were lost time (Polaschek 2000), lost dreams (Calvey and Mee 2011), and loss of income and financial independence (Calvey and Mee 2011). All these contributed towards an overall sense of loss in the participants.

One study found that certain character traits helped some people cope better with living on dialysis and waiting for a transplant (Calvey and Mee 2011). The ability to maintain a positive outlook was felt to be important in preventing depression while waiting for a kidney transplant.

4.7.1.3 Synthesised finding 3: The impact of waiting for a kidney transplant on a person's relationships with others

People who are waiting for a kidney transplant from a deceased donor place value on relationships and being part of a community. The experience of waiting for a kidney transplant from a deceased donor while living on dialysis with ESKD changes a person's relationships. The third meta-synthesis is derived from just one category with four findings (Calvey and Mee 2011; Herlin and Wann-Hansson 2010; Polaschek 2000). Families and relationships were a source of strength and encouragement (Polaschek 2000) but ESKD and living on dialysis while waiting for a kidney transplant could have a negative impact on family relationships with some participants describing feelings of being a burden to their loved ones (Calvey and Mee 2011). Waiting for a transplant caused people to feel isolated by the unusual situation they lived with. This made it difficult to form new friendships and led to feelings of loneliness (Herlin and Wann-Hansson 2010)

4.8 Systematic review discussion

The aim of this review was to gain insight into the experiences of people who were waiting for a kidney transplant from a deceased donor with the objective of providing a foundation to inform the subsequent qualitative study. The 12 studies included in the review generated 37 findings which were then developed into 11 categories and three synthesised findings.

The first synthesised finding showed that people who were waiting for a kidney transplant from a deceased donor were profoundly affected by the experience of living on dialysis with ESKD. The disease and resulting dialysis therapy both had a great impact on their health and normal activities of living. End stage kidney disease is a chronic medical condition characterised by a decline in kidney function to a point where renal replacement therapy, in the form of either dialysis or transplantation, is necessary in order to maintain life (Caring for Australasians with Renal Impairment 2005a; Levey and Coresh 2002). The symptoms of ESKD include anaemia, itch, bone pain, hypertension, fatigue, decreased urine output, loss of appetite, oedema and breathlessness (Pendse and Singh 2001). As well as symptoms of the disease, the effects of the dialysis therapy itself are also intense, including hypotension (Bregman, Daugirdas and Ing 2001), infection (McDonald 2012) and fatigue (Bonner, Wellard and Caltabiano 2010). End stage kidney disease is a chronic, life-limiting illness. The findings showed that people with ESKD have had to consider their own mortality and accept the fact that without dialysis their own kidney function is insufficient to support life. Linked with the experience of facing their own mortality, people waiting for a kidney transplant had an awareness that their transplant would only occur if somebody else died. *"Somebody is dead and I'm alive with their kidney … that doesn't seem right to me"* (Calvey and Mee 2011, p. 205).

In addition to the bodily effects of ESKD and dialysis, the findings also showed that dialysis therapy led to a restricted life with people feeling out of control and dependent on carers, medical staff and machines. The home-based dialysis therapies PD and home haemodialysis had been proven to provide the best outcomes in terms of patient quality of life (Alvares et al. 2012), however they are still time-consuming treatments that require a level of commitment and skill on the part of the patient. When transport and time spent waiting were added onto the treatment time for hospital-based therapies, all dialysis therapies could have a negative impact on normal activities of living. The length of time required to be spent in treatment affected a person's ability to maintain gainful

employment. The ability to work was further restricted when medical appointments, emergencies and malaise were considered, as was the ability to go away on holidays (Herlin and Wann-Hansson 2010; Polaschek 2000). For some people the restrictions on travel mean a separation from loved ones who live overseas or a long distance away (Moran 2008; Shih and Honey 2011).

The second synthesised finding showed that the experience of waiting for a kidney transplant from a deceased donor had a psychological effect on a person's wellbeing. Often this was a positive effect with many of the studies reporting that waiting for a renal transplant gave people hope that dialysis would not be forever (Calvey and Mee 2011; Dekkers, Uerz and Wils 2005; Hagren et al. 2001; Herlin and Wann-Hansson 2010; Polaschek 2000; Rittman et al. 1993; Sadala et al. 2012). People believed that when they got a transplant they could return to something like the freedom they had before they became unwell. *"The hope of a kidney transplant provided the participants with the possibility of returning to a normal life in the future. In addition, it provided them with the strength to endure the experience of being a renal patient"* (Moran 2008, p. 173).

People waiting for a kidney transplant from a deceased donor experience high levels of uncertainty. This includes uncertainty about both the timing and the outcome of the transplant. Uncertainty can result in people experiencing increased stress and anxiety, waiting and hoping for the transplant to happen but having no assurance. The median waiting time for a kidney transplant from a deceased donor ranges from 3.1 to four years (United States Renal Data System 2011; Wright 2011). Study findings showed that providing people with information about average waiting times might contribute to increased psychological pressure. People learned from observation of others that waiting the average length of time did not always mean that it was their turn next. *"I tried hard to keep up on the waiting list for many years; I feel aggravated sometimes. I have been on the transplant list for many years and nothing happened. I hope the next one may be me but I am always disheartened"* (Shih and Honey 2011, p. 7).

Study findings showed that people who were waiting for a kidney transplant gained a psychological benefit from the acquisition of knowledge. Knowledge helped them regain some level of control in their lives. Well informed patients were better able to make choices regarding their care while lack of knowledge was a source of anxiety and stress. In some senses the uncertainty experienced by people waiting for a kidney transplant resulted from a lack of knowledge. While it was not possible to provide all the facts and figures to

alleviate these patients' fears, it was evident that people benefitted from having information made available to them. Health practitioners who cared for people waiting for a kidney transplant should recognise that being on the transplant list brought about both positive and negative feelings. The effect of waiting for a kidney transplant provided hope as well as uncertainty, stress and anxiety.

The third synthesised finding was that people who were waiting for a kidney transplant were part of a community and placed value on relationships with family and friends. The experience of waiting for a kidney transplant changed those relationships. Study findings referred to the participant's social networks of family, friends and the staff and other patients at the dialysis unit (Calvey and Mee 2011; Herlin and Wann-Hansson 2010; Polaschek 2000). These communities were a source of strength and support for participants. Just as the participant had to adapt to the effect of living with ESKD and dialysis, the family members and friends also had to adapt, often taking on the role of carer for the person waiting for a kidney transplant. Some people accept and value these changes in the dynamics of their relationships. *"[It's a] terrific amount of teamwork, it's so much easier with some helping, much more pleasurable, quicker if you work as a team"* (Polaschek 2000, p. 169). For others this increased reliance on others was a source of anxiety and guilt. *"Why did she marry me, if she married someone else she'd get out … she wouldn't be living this kind of life … how unfortunate she was"* (Calvey and Mee 2011, p. 204). The unusual situation of waiting for a kidney transplant meant that participants who were single found it difficult to establish relationships with new acquaintances, reporting feelings of loneliness and isolation (Herlin and Wann-Hansson 2010; Polaschek 2000). Medical communities were another important source of support. People waiting for a kidney transplant from a deceased donor drew inspiration from positive relationships with friends, family members, other dialysis patients and healthcare workers.

4.9 Limitations of the review

Of the 12 studies included in this review, only two included data that was entirely from people who were waiting for a kidney transplant. In the other 10 studies the participants included some people who were waiting along with some who were not. These studies were included in the review because some of the findings illuminated the experience of waiting for a transplant, but in order to exclude evidence from people who were not waiting for a transplant, only findings that specifically mentioned waiting for a kidney transplant were included in the review. This means that there may be more findings that

provide evidence into the experience of waiting for a kidney transplant but which were omitted from the review because it was not possible to tell which category of participant the evidence came from.

4.10 Systematic review conclusion

There is little high quality evidence to describe the experiences of people waiting for a kidney transplant from a deceased donor. There are, however a number of high quality studies describing the experience of living on dialysis and many of these provide insights into the experience of waiting for a transplant (Calvey and Mee 2011; Dekkers, Uerz and Wils 2005; Hagren et al. 2001; Herlin and Wann-Hansson 2010; Kaba et al. 2007; Landreneau and Ward-Smith 2007; Moran 2008; Polaschek 2000; Rittman et al. 1993; Sadala et al. 2012; Shih and Honey 2011; Yu and Petrini 2010).

Synthesised findings of the review conclude that people who are waiting for a kidney transplant from a deceased donor live with the physical effects of a life limiting chronic illness. Dialysis therapy also causes physical side effects and restricts a person's normal life. Waiting for a kidney transplant is psychologically challenging. The transplant is hoped for as it is perceived as providing an escape from dialysis and a return to normal life, but the uncertainty surrounding the timing and outcome of the transplant causes people to feel anxiety and stress. People waiting for a kidney transplant value knowledge, although the information they require to alleviate the uncertainty they feel is not available. They exist in communities and value their relationships with others. The dynamics of these relationships are affected by the experience of waiting for a kidney transplant. People can feel isolated from others leading a 'normal' life, while new relationships are developed within the medical team and community of dialysis patients.

4.11 Implications for practice from the systematic review

There is limited evidence from the review to support the development of recommendations for clinical practice. Healthcare workers caring for people who are waiting for a kidney transplant from a deceased donor should be mindful of the physical and lifestyle effects of living on dialysis with ESKD. Wherever possible, information should be provided to alleviate the stress and anxiety related to the uncertainty of waiting. Staff should consider that the experience of waiting is stressful and that people waiting for a kidney transplant may require support and reassurance. It is also important to recognise that people exist within communities who may also benefit from receiving information and encouragement. By

acknowledging the importance of relationships to people who are waiting for a kidney transplant, healthcare workers should aim to include the patient's family and friends in their care and provide the best source of role modelling behaviour. Significant community members should be included in invitations to appointments and education session with the consent of the person being treated (Level 1 evidence(*Joanna Briggs Institute, JBI Levels of Evidence* 2013)).

4.12 Implications for research from the systematic review

Given the limited evidence obtained from the review, further research to describe the lived experiences of people who are waiting for a kidney transplant from a deceased donor is warranted. Qualitative research designs such as phenomenology and grounded theory could investigate the psychological experience of waiting, and the relationship between hope, uncertainty and knowledge. Quantitative studies using validated tools could also be conducted. By producing more evidence relating to this significant specific patient population, interventions to improve the experience of waiting could be developed and trialled.

4.13 Conclusion

The systematic review presented in this chapter has investigated the question, 'What is it like for people to wait for a kidney transplant from a deceased donor?' The majority of studies included in this review reported the experience of living on dialysis with the experience of waiting for a kidney transplant largely described incidentally. A gap in the literature was noted for a study that specifically investigated the experience of waiting for a kidney transplant from a deceased donor. The following chapters describe such a study.

CHAPTER 5 **QUALITATIVE DESCRIPTIVE STUDY: METHODOLOGY AND METHODS**

5.1 Introduction

The preceding chapters have described the clinical features of ESKD, renal replacement therapy options including kidney transplantation and the effect that waiting for a kidney transplant has on a person's daily life. Through a thorough review of the literature including a systematic review, a gap in the literature has been identified for a study that specifically seeks to answer the question, 'What is it like to wait for a kidney transplant from a deceased donor?' This chapter will describe the methodological approach and the theoretical framework adopted to conduct this study. Methods of participant selection and recruitment will be explained along with the methods of data collection. The process of ensuring that the study was conducted ethically with the approval of the facilities' ethics approval boards will be shown, along with the approach to data analysis and the steps taken to ensure that the findings of the study are trustworthy. A summary of the reporting methods used in this qualitative study has been made using the COREQ (Consolidated criteria for Reporting Qualitative research) checklist (Tong, Sainsbury and Craig 2007) and is included in Appendix 12.

5.2 Theoretical perspective

A qualitative exploratory descriptive research design was used for this study. Exploratory descriptive research involves both 'finding out what is there' and 'describing what has been found'(Sandelowski 2000). In the case of a question such as this one where there is minimal data and no studies relating to the specific experience and patient population, exploratory descriptive research is an appropriate choice of methodology, conducted for the purpose of finding out and exploring unknown phenomena relating to a single topic or population (Huttlinger 2006; Polit and Beck 2012). The participants' recollections and anecdotes represent a moment that may not necessarily reflect the way they view life the next day, nor represent the way another person living with the same realities views the situation (Lincoln and Guba 1985; Lincoln, Lynham and Guba 2011). Each unique viewpoint contributes to the total knowledge about the experience under investigation (Bazeley 2013). What can be known about waiting for a kidney transplant may be revealed by talking to people who are waiting for a kidney transplant and living with on dialysis with ESKD, with each person's experience contributing towards the whole understanding.

5.3 The position of the researcher within the study

Every researcher brings to their research their own formed observations and experiences which have the potential to influence their findings (Doyle 2013). The relationship between the knower and what is known cannot be separated, meaning that it is impossible for the researcher not to interact with the participant in the process of finding out what it is they want to know, or for their biases not to inform the way they interpret what they see (Thorne 2008). The position of the researcher in this study is stated to demonstrate reflexivity – that is the process the researcher has undertaken to identify their own standpoint towards the subject under investigation and to consider the impact their views might have on the conducting of the study and the analysis of the data (Altheide and Johnson 2011). By analytical scrutiny of the researcher's established perceptions, reflexivity enhances the transparency of the study (Denzin 2011).

As the principal researcher in this study, I am a woman who brings 13 years of renal nursing experience to the study along with an awareness of the individual participants' life situations and medical histories. I am also acquainted with the details of the donation process and the medical circumstances leading up to donors giving their organs after death. To a certain extent I share the hopes and fears of the people who are waiting for a transplant, but I have also been saddened by the medical information about the donors, able to piece together details of lives shockingly cut short and generous families left behind grieving. While prior knowledge such as this may be a source of coercion and bias in the data collection and data analysis processes, it is also the case that such an ongoing relationship may contribute to reciprocity and encourage participants to share their stories (Doyle 2013; Harrison, MacGibbon and Morton 2001). It can be difficult for people to articulate their experiences and so an existing relationship with the researcher may provide recognition and support. In this case the researcher's clinical experience gave the inspiration for the study through observation of the wide variety of responses by people who were waiting for a kidney transplant from a deceased donor. Observing some people to endure impatience and anxiety, while others seemed unconcerned and unmotivated, the question of what it is like to live while waiting for a kidney transplant from a deceased donor became a clinically relevant research question.

5.4 Research design

A qualitative descriptive research design was adopted for this study. Qualitative research seeks to describe, "… what people do in their everyday lives and what their actions mean to

them" (Erickson 2011, p. 43). It is concerned with the kinds of things that give meaning and purpose to a person's life and it creates knowledge that provides detailed explanation framed within the context of the individual human experience (Erickson 2011). Qualitative research provides information that would be inappropriate to assess quantitatively, investigating questions that cannot be answered numerically by measurement or statistics (Thorne 2008) but rather producing a rich description of the situation under investigation (Denzin and Lincoln 2011).

Description has been defined as, "… itemizing or documenting something that requires it – telling what it is that one observed" (Sandelowski, 2000 in Thorne 2008, p, 47). It involves finding out what is there and describing what has been found (Sandelowski 2000) and it provides a report of observable facts relating to a question. Descriptive research is used to generate new observations by taking a different approach, moving on from information that is already established and exploring the context (Thorne 2008). In this study the research question asks about the experiences of people, therefore it is appropriate to adopt a qualitative approach. As there is currently little literature relating to waiting for a transplant, the descriptive design will document the characteristics of the experience in broad terms to provide a baseline for further studies.

5.5 Participants and setting

5.5.1 Sampling

A combination of convenience and purposive sampling was adopted to recruit participants for this study. The group may be described as a convenience sample as all of the participants were patients of the renal department at one metropolitan hospital in Southern Sydney, New South Wales (NSW) where the principal researcher was also employed as a transplant coordinator. As the aim of this study is to describe a phenomenon about which relatively little has been documented, it is appropriate to use a convenience sample, but it is acknowledged that the results may be specific to the care provided at the particular unit (Polit and Beck 2014; Thorne 2008). The group may also be described as a purposive sample. Specific criteria were applied when selecting people to participate to ensure that those who took part had personal experience of living with the situation under investigation (Bazeley 2013; Polit and Beck 2014). A purposive sampling method selects participants based on pre-determined criteria and is commonly used in

qualitative research where a specific experience is under investigation (Burns and Grove 2011).

Sample size was initially determined by the number of people who attended the focus groups. The potential participants of this study were a time-poor group of people, maintaining dialysis therapy as well as work and family commitments. In order not to add to the burden of appointments, only those who responded to the letter and follow up phone call were included and no further attempts were made to recruit more participants at that time. In qualitative research it is important to show the adequacy of the sample by achieving data saturation, where the existing findings are consistently repeated and where no new findings appear (Morse 2015). In this study the data from both focus groups was remarkably consistent, with participants voicing the same concerns in both groups. Data saturation was reached with the six participants who took part.

5.5.2 Eligibility criteria

To be eligible for this study people had to be undergoing dialysis therapy for ESKD and be active on the National Organ Matching System (NOMS) waiting list for a kidney transplant from a deceased donor. People who could not communicate in English were excluded from the study because focus groups were the chosen method for data collection and it was felt to be impractical to use an interpreter in a focus group environment (Burns and Grove 2011). As the study was seeking to explore the experience of adults, people under the age of 18 were excluded.

5.6 Recruitment

Initially permission was sought from all the nephrologists in the department to approach those people under their care who were on the waiting list for a kidney transplant from a deceased donor to take part in the study. The letter of invitation was signed by the Head of the Renal Department who was instrumental in promoting the research (Appendix 7). People meeting the eligibility criteria were sent the letter of invitation and a participant information sheet (Appendix 8) explaining the nature of the research. The contact information for the principal researcher was included in the letter. People were asked to respond by phone to indicate their willingness to take part in the study and the letters of invitation were followed up by a phone call from the principal researcher two weeks later to confirm whether or not they would be able to attend. As the principal researcher was involved in the clinical care of the invitees, steps were taken to ensure that they

understood that their participation or non-participation would have no effect on their treatment. The participant information sheet (Appendix 8), consent form (Appendix 9) and revocation of consent form (Appendix 10) stated that participation was voluntary and would not influence their clinical care. Potential participants were also advised verbally by the principle researcher that taking part in the study would make no difference to their day to day care. The information sheet explained that the participant's written consent to take part would be required and consent forms (Appendix 9) were signed on arrival at the venue before the focus groups started.

5.7 Ethical considerations

5.7.1 Ethical process

Ethical approval to conduct this study was obtained from the Human Research Ethics Committee (HREC) of South Eastern Sydney Local Health District (SESLHD) and the University of Wollongong with Site Specific Approval (SSA) from the hospital at which the research was conducted. The research was deemed to be of low/negligible risk according to the Australian national ethical standards.

The involvement of the Head of the Renal Department in signing the letter of invitation and the transplant coordinator as the principle researcher could be viewed as coercive, but the participant information sheet clearly stated that participation or non-participation would have no effect on their ongoing clinical care. This information was repeated verbally in the follow up phone calls and the focus groups.

5.7.2 Privacy and confidentiality

The focus groups took place in a meeting room which was undisturbed and private. Participants were informed that the information they shared in the focus groups would only be used for the purposes of the research and would not be reported to anyone outside of the group. Participants were also asked to respect the confidentiality of the other members of the group in not repeating what was shared to other parties. The verbatim transcripts of the focus group discussions were de-identified and pseudonyms were created for the participants to be used in all publications (Morse and Coulehan 2015). The digital documents and sound files were saved on a password protected computer for the duration of the study to be deleted after five years as per the National Health and Medical Research Council (NHMRC) requirements.

5.7.3 Risks and benefits

It was acknowledged that there was a risk of causing distress to the participants by encouraging them to reflect on the experience of waiting for a transplant. This was made clear to people on the participant information sheet (Appendix 8). A second facilitator was present in each of the focus groups in order to provide comfort and assistance to people at the time if they became upset during the discussion. An arrangement was made for the renal social worker to offer counselling to those for whom the discussion raised deeper psychological discomfort. Literature has shown that people can benefit from being given the opportunity to tell their story (Nel, Romm and Tlale 2015). The focus group environment provided participants with an opportunity to air their point of view and form relationships with other people in a similar situation to themselves.

5.8 Data collection

Focus groups were used as the method of data collection. Focus groups are designed to foster a sense of collaboration between group members in order to explore a topic and achieve a deeper level of discussion than would be possible with individual interviews alone (Kamberelis and Dimitriadis 2011, p.546). The use of focus groups as a method of data collection originally has its roots in the discipline of social science and was later adopted by market researchers as a means of gathering consumer information (Halcomb et al. 2007; Kamberelis and Dimitriadis 2011). An important feature of focus groups is the social interaction between participants which enables them to co-construct an interpretation of the experience that represents their own view (Lehoux, Poland and Daudelin 2006). It has been suggested that focus groups may be more effective than interviews as they create a social dynamic in which it is easier for people to form opinions and create a shared perspective (Hildebrandt 1999; Thorne 2008). They encourage people to take part who may not be confident on their own or who may feel they have nothing worthwhile to contribute (Greenwood, Ellmers and Holley 2014; Kitzinger 1995). Criticisms of focus groups would be that that social dynamic can make it harder for people to express more diverse opinions and that they have the potential to be dominated by the most articulate participants (Cleary, Horsfall and Hayter 2014; Thorne 2008). Skilful facilitation is required to ensure that all participants are given the opportunity to speak, and interact with one another (Thorne 2008). Focus groups were used in this study to capitalise on the networks that exist within communities of dialysis patients. It was hoped that as the participants

shared many experiences in common the focus groups would stimulate conversation and provide a rich source of data for analysis.

Two focus groups were scheduled to take place at a meeting room on the hospital campus. The place and space used for data collection have been found to play an active role in the interactions between the participants, the facilitator and the data, and have an effect on the sense of authority, security and confidentiality within the group (Gagnon et al., 2014). By locating the focus groups on the hospital campus it was hoped that participants would find it easy to attend as they would already be familiar with transport arrangements such as travel time and parking availability. However a meeting room was used in an area of the hospital that was not normally visited by renal patients in order to provide a relatively private environment away from the usual clinical setting and to emphasise that the focus group was not part of their clinical care (Polit and Beck, 2014, Halcomb et al., 2007).

The first focus group was scheduled for a Monday at 10.00am and the second focus group was scheduled for a Tuesday at 2.00pm. As in-centre haemodialysis operates Monday, Wednesday, Friday morning and afternoon shifts, and Tuesday, Thursday, Saturday morning and afternoon shifts, these days of the week and the times were chosen to maximise the number of patients who could participate in the focus groups.

In qualitative research it is more important to show the adequacy and appropriateness of the sample rather than a large number of participants. Adequacy refers to the phenomenon where data is repeated by different participants in different groups, and appropriateness indicates that the focus group participants met the necessary criteria to be able to speak with authority about the situation being studied (Morse 2015).

The focus group questions followed a semi-structured format. A semi-structured question guide was developed with initial questions informed by the literature and the principal researcher's experience as a clinician as follows:

> What are your experiences of being on dialysis?
>
> What are your thoughts about getting a kidney transplant?
>
> What was your experience of first being activated on the waiting list for a kidney transplant?
>
> What is your experience of being on the waiting list for a kidney transplant now?

What difference has being on the waiting list for a kidney transplant made to your day to day life?

Can you think of anything that would improve the experience of waiting for a kidney transplant?

Where areas of common interest developed in the conversation the facilitator asked unscripted questions to explore these topics more deeply. Each focus group was conducted by two facilitators. In the first group the primary researcher of the study watched and listened as the group was led by an expert with extensive experience in leading focus groups. The primary researcher then led the second focus group with the support of one of her university supervisors. In this way a novice researcher was able to learn and practise a new skill with support and supervision. The second facilitator was also available to provide support should any of the participants become upset, document field notes about any non-verbal communication they observed and pick up lines of discussion that had not been fully discussed. The benefits of dual moderated focus groups have been documented (Hudson 2003; Kamberelis and Dimitriadis 2011). Only group participants and researchers were present in the focus groups. The focus group discussions were recorded with a digital sound recording device. The audio files were uploaded and transcribed verbatim by a commercial transcription service. Audio recording and verbatim transcription have been recommended as techniques to enhance the credibility and authenticity of the data (Polit and Beck 2014) and are commonly used in qualitative data collection. Pseudonyms for the participants were created and the transcripts were reviewed by the principal researcher to remove any identifying information.

5.9 Data analysis

The purpose of data analysis is to transform and organise the raw data in, "…a new, rich, or expanded way" (Thorne 2008, p. 175) that gives meaning to the issue under investigation. It aims to provide a theoretical summary or a reconceptualization that presents the data in a fresh way that is recognisable to participants and clinicians.

The first part of the data analysis was immersion in the data. Although the audio recordings were transcribed by a professional transcription company, the researcher listened to the recordings while concurrently reading the transcripts many times. Field notes taken during the focus groups were added to the transcription documents to add

more detail about participant interactions and other non-verbal information. By repeated listening and reading of the transcripts the content of the data became very familiar.

The second part of the data analysis process was coding; identifying and labelling all the different elements contained within the data while looking for commonalities and differences. In this study interview transcripts were coded using Nvivo software, a commercial product developed to assist with the management of qualitative data during analysis (Bazeley 2013). No pre-conceived coding system was used, but instead the codes and the categories were derived directly from the data (Brewer et al. 2014). By breaking the data apart into its component pieces the researcher was then able to consider how the different elements relate to each other (Hsieh and Shannon 2005).

The next stage of analysis scrutinised the data for patterns and variations. Initial codes were intentionally broad to allow the data to be interrogated repeatedly in order to find out in what different ways the concepts within the data were related to each other (Thorne 2008). The development of sub-categories and categories through reflection sought to convey the underlying meanings, concepts and interpretation of the data (Sandelowski and Barroso 2003). During this analytical process the researcher remained critical and reflective towards their own pre-knowledge, while attempting to hear what the participants were communicating at that moment (Thorne 2008). The process of data analysis went through many stages as the researcher considered what concepts were being revealed. The researcher's prior knowledge provided a practice context from which the data was interpreted (Thorne, Kirkham and MacDonald-Emes 1997). Links and relationships between sub-categories were established and the data was organised into the final conceptualisation to provide an account of what it is like and how it feels to wait for a kidney transplant from the participants' point of view.

5.10 Trustworthiness

The trustworthiness of a qualitative study lies in the transparency of the data collection and analysis processes, and in establishing that the findings are credible (Polit and Beck 2014). Although participants may report completely different experiences to each other this diversity contributes to the breadth of knowledge of the experience. The reported findings should reflect the experiences and viewpoints of the participants rather than that of the researchers. Various methods are used to ensure validity. These are described below.

5.10.1 Transparency

Transparency refers to the clear documentation of the chosen study methods and the findings that resulted (Altman and Moher 2013). In the method of data analysis adopted for this study, the findings came directly from the experiences of the participants as reported in the focus group transcripts and not from pre-conceived criteria dictated by the researcher (Shenton 2004). As the primary researcher was a novice, analysis of the data was carried out with the support of the supervisors for her post graduate degree, and by peer debriefing. Preliminary findings of the study were presented to a group of specialist transplant nurses at a national conference. This feedback provided consensual validation that these were sound conclusions. Peer debriefing helps to provide transparency to the data analysis process (Bazeley 2013).

5.10.2 Credibility

Credibility is a measure of whether the study methods and findings accurately answered the chosen research question (Oliver 2012). In this study the chosen methodology, data collection and data analysis methods are established as effective in answering qualitative questions and have been used in similar studies relating to the experiences of a group of people with a shared clinical experience (Brewer et al. 2014; Gibson et al. 2013; Ravenscroft 2005). Adopting methods that have been used in other similar studies strengthens credibility (Shenton 2004).

The authenticity of the findings compared to what else is known about the topic is another method of establishing credibility (Thorne 2011), sometimes referred to as triangulation (Bazeley 2013). A systematic review of qualitative literature was conducted to inform this study, although the primary focus of the studies included in the review was the experience of living on dialysis. The focus group data showed congruence with the three meta-syntheses found in the systematic review which suggests that the study has credibility in relation to what else is known. The use of an alternative method of inquiry, such as systematically reviewing the literature, to research the same question is another strategy for establishing the credibility of a study (Shenton 2004).

5.11 Conclusion

This chapter has described the methodology and methods used to conduct this study into the experiences of people who are waiting for a kidney transplant from a deceased donor. It has listed the data collection and data analysis methods that were adopted. As a piece of

qualitative research, transparency in all these details enhances the trustworthiness of the study and its findings. The next chapter will report the findings of the study.

CHAPTER 6 **QUALITATIVE DESCRIPTIVE STUDY: FINDINGS**

6.1 Introduction

This chapter reports the results of the data analysis presented as the findings of the study. Four main themes were identified in the data: living on dialysis is physically and mentally restricting; living with uncertainty; altered relationship dynamics; and feelings towards the deceased donor. Within these four themes were nine subthemes. A summary of themes and subthemes is shown in Table 6 below.

Table 6: Themes and subthemes

Theme	**Subtheme**
Living on dialysis is physically and mentally restricting	Transplant means freedom from dialysis
	Acceptance of the wait as a normal part of life
Living with uncertainty	An ongoing wait
	Fear of losing hope
Altered relationship dynamics	Valuing family support
	Protecting loved ones
	Supported from within the dialysis community
Feelings towards the deceased donor	Pragmatic appreciation
	Identifying with another's loss

In this chapter a brief biographical description of the focus group participants is followed by a detailed description of the themes and subthemes including data that illustrates each finding.

6.2 Demographic information – an introduction to the participants

Six people took part in the focus groups, with one group having four participants and the other two. Each participant is described below including information about their age, marital and employment status, family or social support networks, ethnic background and length of time on dialysis. A summary of the demographic information is given in Table 6.

Three of the participants did not speak English as their first language but transcript quotes have been left unadjusted in order to preserve the original meaning of their words.

Table 7: Demographic information

Focus group	Pseudonym	Age	Marital status	Mother tongue	Type of dialysis therapy	Time on dialysis
2	April	47	Single	Chinese	Home HD (initially PD)	3 years
1	Barry	50	Married	English	Home HD (initially hospital HD)	10 months
2	Cathy	63	Married	Greek	Home HD (initially hospital HD)	4 ½ years
1	Mary	29	Single	English	PD (initially hospital HD)	6 years
1	Vincent	52	Single	Filipino	PD	2 years
1	William	52	Married	English	PD (initially hospital HD)	3 years

April was a Chinese lady in her late forties. She was single and lived with her adult son while most of her relatives including her aging parents, lived overseas. She had been on dialysis for three years, initially on PD, but had recently transitioned to haemodialysis and was dialysing independently at home. April worked in corporate business on short term contracts.

Barry had been on dialysis less than one year at the time of the focus group. He was an Australian-born married man in his fifties, with three teenaged children. Barry managed his haemodialysis independently at home and in this way was able to combine renal replacement therapy with a demanding job for an international company, plus extensive volunteering commitments with his children's activities.

Cathy was a Greek lady in her sixties, married with grown up children, grandchildren and a network of friends and relatives both in Australia and in Greece. She had been on dialysis for four and a half years, starting in the hospital, but eventually mastering haemodialysis at home. Her adult son had recently had a stroke and returned to live at the family home so that Cathy could help him with his care.

Mary was a single woman in her late twenties. Australian-born, she came from a large caring family of South American background. She had been on dialysis for six years, initially

on hospital haemodialysis, but had switched to PD after a few months. She completed university while on dialysis, but once she graduated had found it impossible to find work that she could fit around her medical appointments and dialysis regimen.

Vincent was a single man in his fifties who had migrated to Australia from the Philippines many years ago. Many of his family members still lived overseas, including his elderly mother. Vincent had been on PD for two years, and was the only participant who had not had any experience of haemodialysis. He had a part time job in the retail industry.

William was a married, Australian born man in his fifties who worked in his own business. His renal disease was hereditary and so he had also observed the experiences of his two brothers. One brother had received a kidney transplant several years earlier, and the other was not yet on dialysis. William had been on dialysis for three years, initially on hospital haemodialysis but switched to PD after a few months.

6.3 Living on dialysis is physically and mentally restricting

The data show that the experience of waiting for transplant is contextualised within the experience of living on dialysis. The greatest challenge for people who are waiting for a kidney transplant is not specifically the waiting, but living on dialysis while they wait. Dialysis impacts life in many ways as it limits peoples' ability to work, travel and use their time freely. Within this theme of restriction are two subthemes: the thought of getting a transplant gives people hope; and the wait becomes accepted as a normal part of life.

Mary commented,

> *Yeah, the waiting list pretty much doesn't - the dialysis is the one that affects you physically and mentally, but being on the waiting list? Not really.*

Mary found the effects of dialysis to be both physical and psychological. She described how the relentless cycle of being on dialysis impacted her life, often all day and every day.

> *I would have haemodialysis and then the day that I had off was pretty much in bed all day and then by night I was feeling a bit okay to get out of bed then to go back to the haemodialysis [the next day].*

Participants talked about how living on dialysis not only affected them physically, but also restricted their everyday activities of life. The hours set aside for dialysis therapy limited

the amount of time available for other pursuits while the amount of activity they could attempt in between dialysis sessions was restricted by the side effects of the therapy.

> *I'm functioning - on the day that I do it you're a little bit flat in the morning. To be honest, you're not lively … I can still function, a little bit slower*. *(*Barry*)*

Participants felt that time spent on dialysis restricted their lives by taking up hours of time that could otherwise be spent in fruitful activity. Cathy and April both expressed frustration that time on dialysis dragged by slowly:

> *… you have so much spare time you have attach the machine, you can't really do anything. For three hours I'm perfect. After three hours, the hours never go.* (Cathy)

> *I feel like I have to watch something, watching some movies or something otherwise the time like never finish.* (April)

The hours of time spent attending to the requirements of dialysis therapy affected other areas of the participants' lives. The impact of dialysis on employment was a commonly reported restriction. Mary's experience illustrates how difficult it is for a person to continue in employment while coping with ESKD and dialysis:

> *I finished university, wanted to get back into the workforce and my health has been such a roller coaster ride that I can't actually do full time work. So went down to part time and then was in hospital for like a month so then had to drop work completely. So now I'm trying to get back into the workforce again.*

William described the effect of dialysis on his work life:

> *You can't say to your friends, geez I saw a job in the paper I'd really love - oh no that's right, I can't go for that. But I'm just doing what I can … I just still keep on working every now and again, casual.*

April, William and Vincent had all reduced their work hours to part time as they found the demands of full time work to be unsustainable. William also referred to effect this had had on his finances. His reduced working hours had meant a significant impact on some financial investments he had taken out shortly before he became unwell.

So the day-to-day things, not only come from the physical aspects of dialysis but the fact it can have a financial - I was just unlucky that I made huge money investments that were based over a long period of time to return, right, and I had to sell them virtually three to six months after buying them and that just doesn't work. So financially there was that big change.

By restricting their ability to work, dialysis affected the participants' economic wellbeing, not just because of the cost of medical treatment, but also by reducing the amount of money they were able to earn.

People reported how dialysis restricted their freedom to travel overseas. Four out of the six focus group participants had significant family links to countries overseas including April and Vincent who both had elderly parents living outside Australia. For them dialysis meant not being able to see their parents.

You know after this PD and the home dialysis I think we just attach [to] the machine now … you can't do a lot of things. I want to travel. I want to back to China to visit my parents. (April)

Mary was the only participant who had managed to travel overseas while on dialysis. Although she was glad to have made the trip, the additional planning and uncertainty about whether she could get dialysis while she was away added to the overall stress of the journey

Planning several months ahead and you're worried is my machine going to arrive and is everything going to be okay? Are the products going to arrive? It's extra stress. (Mary)

Barry had three adolescent children and overseas family holidays had been a normal part of life up until his diagnosis with ESKD. He spoke about how he was trying to minimise the impact of dialysis on this family tradition:

I said don't stay because of me. So I'm trying to pack them off to Disneyland or something at the moment. That's a hard one, because the youngest one is only 12, nearly 13. He wants you there, whereas the others, older teenagers, well we'll see you when we get back. But deep down they want you there as well.

Overseas travel had been a regular activity of life for many of the participants prior to dialysis and the resulting restrictions on travel were keenly felt.

The experience of living on dialysis was described as socially isolating with friends from outside the dialysis world. Although physically able to take part in activities, participants felt disconnected from their friends, nor fully able to relate to them their own experiences. Mary commented:

> *… all my friends when we go out for dinner or something, they're all talking about work and stuff and I'm just like, oh I can't talk about work. I can't participate in the conversation. Just little things like that.*

Although Mary had completed her university course while on dialysis, the symptoms of her ESKD had meant that she had been unable to find work after she graduated. Being the only unemployed member in her group of friends meant that she felt disconnected from the general conversation about work while her own experience of life on dialysis was foreign to her friends.

William had a similar experience, relating how he and his friends used to go away for golfing weekends. Once he started on dialysis he felt it wasn't the same:

> *Apart from the fact that I go away with the golf club every now and again, but they're always on the turps... What a waste of time, you know. Like you're there, you're just used as a driver.*

Like many people who are on dialysis, William was on a strict fluid restriction limiting the amount of liquid he can drink in one day to 1.5-2litres. Even though he could still attend the golfing weekends with his friends, the fact that he could not drink with them in the evenings meant that he felt excluded. His experience of life was so different to that of his acquaintances that they could not relate as they had done before dialysis.

Waiting for transplant from a deceased donor in Australia means having to be on dialysis and the data show that it is dialysis that takes priority over everything else in life. Living on dialysis while waiting for a kidney transplant confines normal activity in many ways. It restricts a person's ability to pursue the activities they would normally hope to achieve if they were well such as have a career, travel overseas and be financially independent and it can lead to feelings of social isolation..

6.3.1 Transplant means freedom from dialysis

When asked to reflect on how they felt about getting a kidney transplant the participants' responses showed that they viewed it as something necessary if their life was ever to return to normal. A future that included a transplant gave them hope that the physical and mental restrictions of life on dialysis would not continue for ever. April described what getting a kidney transplant would mean to her:

> *Kidney transplant I think is very good. I warm to it because I think first bring me the freedom. That's I really want. I want the freedom … I want lots of freedom - because this one [dialysis] definitely does affect my life.*

Her emphatic repetition of the word 'freedom' illustrated April's underlying sense of confinement while living on dialysis. She stated that living on dialysis had made a big difference to her life and she believed that a kidney transplant would bring her the freedom she had lost.

In a similar vein Mary talked about transplant as a necessity to regain a normal life:

> *… something that has to be done for me to get better and get my life back on track. So I really hope it's soon, because I've been waiting for so long.*

The phrase "something that *has to be done*" showed the inevitability that Mary felt of a kidney transplant being the only way to get her life on track. On dialysis her life she felt her life was off track, out of control and heading in a direction she did not want to go. The burden of waiting "so long" was clearly heavy on her. She hoped a transplant would allow her the freedom to direct her own life and make her own choices and decisions unrestrained by dialysis.

For Cathy the restrictions of dialysis affected not only her but her whole family.

> *I'm waiting for kidney for myself, for my family. I like to do other things. That's why I'm waiting for a kidney. I want to have normal life.*

While living on dialysis Cathy could not choose to live exactly as she pleased. There were other things she would like to do, not just for herself, but also for her family. The only way for her to have the freedom to choose was for her to get a kidney transplant.

Participants accepted that dialysis was necessary to maintain life, but because of dialysis they lacked the liberty to make their own choices and freely live the way they wanted to. A kidney transplant was seen as a way of escape from their dialysis imprisonment. Being

active on the transplant waiting list gave hope that life on dialysis would not have to be endured for ever.

6.3.2 Acceptance of the wait as a normal part of life

Over time the experience of waiting for a kidney transplant became an accepted part of the participants' daily life. The data show that while the restrictions of dialysis loomed large in life, the transplant waiting list did not feature highly. The wait for a transplant had been normalised, making it hard for participants to articulate any actual effect of waiting on their day to day lives.

April's comments illustrate how her feelings towards getting a kidney transplant had changed from the time she was first put on the waiting list. She said:

> *Yeah, initially I'm really worried about all the phones, especially when I'm working; phone always attach me, but after a while I don't care. I feel like it's not coming; don't worry, I just leave it …*

Her relationship with the phone is indicative of her feelings about a kidney transplant, as people on the transplant list have to be contactable at all times in case a kidney becomes available. Her words showed that the initial state of readiness diminished as time went by. After a while she stopped taking all her calls and just accepted that she was on the list.

Barry explained it in this way:

> *I don't wake up every day thinking hopefully today ... I'm on the list. It will happen when it happens.*

The possibility of getting a transplant did not feature highly in Barry's day to day thoughts. Although Barry hoped to get a transplant one day, this comment demonstrates that he did not feel it was likely to happen and therefore he did not think about it very much. Waiting for a transplant had been accepted as a part of his normal life.

Vincent agreed:

> *I am actually not thinking about it over and over again. If it will happen it will happen. … Because I still work part-time, so I never think about the waiting list. Because I normally just do the same, more or less the same thing what I did before. So I didn't really think about it.*

Vincent attributes not thinking about the transplant list to the fact that his life is “more or less” the same as before. However his comment, “If it will happen it will happen” is similar to Barry’s and shows that Vincent had accepted the wait as a normal part of life.

This sense of acceptance is captured by the participants’ use of idioms to describe their situation. Barry and Vincent’s use of the phrase, “It will happen when it happens”, has already been documented, but other participants used similar expressions to describe their feelings of powerlessness.

Mary said:

> *… this has to be done, what can you do? I just have to go with the flow see what happens*

The expression “Go with the flow” conjures an image of being swept along by a strong flowing current, unable to pull free or change direction.

William said:

> *No one would ever wish this on anyone. But at the same time, it is just what it is.*

Cathy said:

> *… I'm looking forward for a kidney and whatever is coming is coming.*

Another metaphor that William used was to describe the wait as a game. All that a person could do was play by the rules and wait for their number to come up. He said:

> *… [They said] you're a common garden type variety person. You’ll have a good chance of getting a transplant. To me that's a funny comment because if you're common that means that there's going to be a lot more common people on the list. It’s just a percentage game.*

William described waiting for a kidney as a game of chance, “a percentage game”. A person won when their number came up and nothing they did made any difference to the outcome.

Cathy referred to luck when she said:

> *I continue to wait if I'm lucky. If I'm not lucky, you can't do nothing else.*

Chance and luck cannot be affected by any action. Like the phrases “It will happen when it happens”, “Go with the flow”, “It just is what it is” and “Whatever is coming is coming” they

reflect the immutable nature of the experience of waiting for a kidney transplant. The participants' use of these metaphors and idioms captured a sense of acceptance towards the situation they found themselves in. No matter what they did, they could not change the experience or make it end, so they accepted whatever would happen to them. The desired transplant would occur at some unpredictable time in the future and until that time the wait would continue, unaffected by anything they did.

6.4 Living with uncertainty

The data showed that people waiting for a kidney transplant live with uncertainty. Within the data about uncertainty were two distinct subthemes. Firstly was uncertainty about the timing of the transplant and how long they would have to wait. Secondly was uncertainty about the outcome of the transplant and whether or not it really would bring them the freedom that they hoped for. This uncertainty about the outcome of the transplant led to the participants expressing fear, not just of something going wrong, but of having to live on dialysis indefinitely without any hope for escape.

6.4.1 The uncertainty of an ongoing wait

A major difficulty with waiting for a kidney transplant is that there is no way of predicting how long the wait will be. Uncertainty about the timing of the transplant was described by participants in both focus groups and caused considerable discussion. Suggestions were made for giving people more facts about when the kidney transplant would come and participants were anxious to be given any information at all that could tell them when they were going to be called.

When asked if there were any ways of making the experience of waiting for a kidney transplant better William said:

> *Could I just - I know that there's a list, but do you ever find out where on the list you are and is this something that you guys question of whether it's worthwhile telling people or - I suppose it depends if you're two and you're 220.*

As the discussion continued William himself then argued against his idea, acknowledging that if a person was told they would get a kidney in the next two weeks and then did not, that would be worse than not knowing at all. He also noted the difference between a person being encouraged by being number two on the list or being demoralised by being told they were number 220. However his question and his comment, "I've always

wondered you know", display a deep desire for more information to reduce the uncertainty in his life and allow him to plan for the future.

The identical question was raised in the second focus group by April who said:

> *I don't know the system can inform you to say you are very close; just something ready; you're hoping will you. I don't know is that how it works or not?*
>
> *Why you not inform how many people in front of us? You shouldn't tell that? No, that's a secret.*

April and Cathy discussed the subject and, as in the first focus group, determined that it might be more stressful for a person to know where they were on the list. April's comments also showed how much she wanted to know how long she would have to wait. Despite understanding on one level that it really was not possible, and maybe not beneficial, for her to know when she would get a kidney transplant, her language revealed doubt and even hinted at thoughts of a conspiracy.

People on the transplant waiting list live with uncertainty. While being constrained by the dialysis regimen, they have no way of knowing how long it will continue. 'How long will I have to wait?' is the question they want answered. As it is impossible to say, they continue to live with uncertainty.

6.4.2 Fear of losing hope

Despite wanting and needing a kidney transplant, participants expressed fear about what might happen when the transplant came. Participants described concerns about the uncertain outcome of the transplant and whether it would really give them everything they hoped for. Part of the process of joining the waiting list for a kidney transplant was that all the participants received education about the risks and benefits of transplantation. In the focus groups participants showed that they had heard and understood this information. While they focussed on the benefit of regaining the freedom to live a normal life, they were also very aware that a kidney transplant was not a guarantee of a problem-free future.

Despite a transplant giving the hope of freedom, ambiguity about the final result and the risks of adverse effects also caused fear:

> *To be honest it's still a little bit scary in the transplant, but that's one way to get you back to normal life … so I like transplant, but only little bit scare me*

is things because some people tell me the story about you might be easy to get cancer or might be - but that's little bit scary things (April)

April once again acknowledged that getting a kidney transplant was the only way she was going to return to a normal life, but this time she said the prospect was scary. Her comment about getting cancer related to information she heard in the education sessions. Immunosuppressive medication must be taken life-long after a transplant and does increase a person's risk of developing cancer.

Mary also used the word "scary" and described the ambivalent feeling of wanting something and yet not wanting it. She said:

Well for me it was more, it was scary at the same time. Like I thought, okay I want to get the call, but at the same time, the day I do get the call I don't know - because straight away you have to go into hospital and stuff …

Mary's words showed that she wanted to get a kidney transplant, but that she knew it would completely disrupt her life. She gave the specific example of "go into hospital" and then summarised the rest as "stuff" followed by a pause. The word "stuff" referred to the surgery, follow up and the unknown outcome. Mary wanted to get a transplant, but she also feared facing the new set of problems that it might bring.

Cathy also described the complex emotional mix of hope and fear:

Sometimes when the phone ring I say oh no is it hospital? My heart is [beating] like this. I'm thinking the operation; scared me, the tablets after the operation.

Despite being something that she wanted, the thought of the actual day of the kidney transplant scared Cathy. She was scared of having an operation and scared of the medication she would have to take afterwards. Again this may reflect what she had been told as part of her education about the benefits and risks of transplant. As long as the transplant was an event at some abstract time in the future it was something that she welcomed, but when she thought about it happening in reality at that moment, then the risks stood out more clearly to her and she was fearful.

Despite fearing the surgery and its ambiguous outcome, participants also feared a future where transplantation was not a possibility:

(April) *…if you're not on the transplant list you feel, oh my god! You think about your rest of life; feel bad like this until you…*

(Cathy) *…die.*

(April) *…the day you're gone.*

Despite never having met before, the two women seem to understand each other so well on this matter that Cathy finishes April's sentence. The thought of life without the possibility of a transplant left them with only dialysis until the day they died. Without the hope of a transplant they feared the rest of their lives would be spent feeling bad "like this" on dialysis. They feared losing the hope of an escape from dialysis.

As well as giving the hope of freedom from dialysis, waiting for a kidney transplant also brought fear. Participants hoped to be released from dialysis, but they were aware that the outcome of the transplant was not certain and that many things could go wrong. Although dialysis held them back from living a normal life, its familiar routine felt safe when compared with the unknown prospect of leaving and starting a new chapter with a kidney transplant. People waiting for a kidney transplant live with the uncertainty of wanting something and yet not knowing when it will happen or what the outcome will be.

6.5 Altered relationship dynamics

The focus group discussions showed that living on dialysis while waiting for a kidney transplant altered a person's relationships. Within this theme, three subthemes were evident. Some relationships were strengthened by the experience of facing difficulty together and led to the participants placed greater value on their family's support. As a result of this increased appreciation, participants were observed to protect the people they loved from distress by downplaying the negative effects of their disease and the dialysis therapy. Thirdly, participants developed new connections were formed within the dialysis community that became another important source of support.

6.5.1 Valuing family support

The data showed that people had a heightened appreciation of the help and encouragement they received from their family members while they waited. There were many comments like Mary's who credited her family as her primary source of support:

Like myself as well, my family has been my driving force I guess. They're always there, yeah, so for me, like my family's just been so important.

Barry credited his wife as a great source of strength and recognised the importance of having someone to provide assistance through the experience.

> *My wife's very supportive with me with it. Honestly, they're the ones that get the hard part … I think you need that support mechanism. I don't know how you'd cope. Having someone there to support, I think is a really important thing to - just sometimes to talk it out with.*

Cathy's family provided her with the motivation to continue on dialysis.

> *See I got four grandchildren and when I am doing dialysis sometimes when I'm too stressing I said you do it for yourself or you do it for your grandkids.*

With the diagnosis of ESKD and the need for dialysis these significant relationships had become more valued by the participants. Their family members gave practical support and emotional inspiration to continue on with dialysis as they waited each day.

6.5.2 Protecting loved ones

Whilst appreciating the help and support of family members, participants explained how they tried to shield their loved ones from the full impact of their illness and the burden of the dialysis therapy. Mary's comments illustrate how she chose to withhold information from her family to prevent them from worrying about her. She describes how she lied to her father rather than upset him when she was feeling unwell.

> *With my dad, it's more if I'm sick I'll call him … and he'll be like, how are you? I'm like, I'm good, I'm good. I could be really bad but I will tell him I'm perfect and he'll be like … are you sure? I'm like yeah dad of course, I'll tell you if I'm sick, but I never do. I do tell my mum though. I'll be like, mum I feel so bad, but don't tell dad because you know how dad is.*

Vincent described a similar experience of keeping information to himself when he was starting on dialysis:

> *I knew that I got a problem with my kidneys since 1996. … and no, I didn't - even my family, my sisters I never tell them about that I have a problem. Just really no one knew actually. Then I got my tube [PD catheter] so I didn't tell anyone that I got a problem because I didn't want them to worry, especially my mum because she was very old already. Then I just keep it to myself.*

All but one of the participants described how they chose to withhold information about how sick they were in order to spare their loved ones from worry.

Another example of participants hiding their feelings was seen in people who had experienced a family member come forward as a potential living kidney donor. Participants reported feeling a burden of gratitude and guilt at the prospect of a family member undergoing unnecessary and possibly harmful surgery to benefit them. When the potential donors could not proceed the participants reported mixed feelings of disappointment at not getting a transplant, but also relief because of the responsibility they felt towards the donor's wellbeing. Vincent told of his experience of a potential live donor who came forward but who eventually changed his mind:

> *… after four months when he decided not to so I actually don't feel bad because I was thinking also about his family, you know, his kids. Because he got young kids so I said, it's okay; because you know … he worried that I won't be friends with him anymore. No, no it's okay, I said, I told him, it's okay, you know, because you got your family, young family and he married, five kids, you know. If ever something happen to him, it would be on my conscience. So it's okay.*

Although he wanted the kidney transplant, when the donor changed his mind Vincent rationalised his disappointment by thinking of the man's family. He suspended his own happiness about escaping from dialysis by the thought of how indebted he would have been to them if there had been any ill consequences for the donor.

Several of Mary's family members had been tested as potential donors but none of them were found to be medically suitable, including her father who had been very upset that he could not help his daughter in this way. Mary described her feelings of relief:

> *I got family members tested, so both my parents and my younger sister got tested, but neither one could donate. So in a way I was relieved, because I had the fear that something might happen to them. So in the back of my mind and I secretly didn't tell them, but I was really relieved.*

Although each potential live donor had come forward voluntarily without any coercion, Mary felt responsible and expressed relief that they could not donate. However she kept her feelings of relief a secret, disconnecting herself again to protect her family members

from further hurt. While the would-be donors acted out of an altruistic desire to help, Mary felt both indebted and guilty.

6.5.3 Supported from within the dialysis community

While people reported feeling isolated from people in their non-dialysis social circle, they formed new connections within the medical system and the dialysis community. The stories of these fellow dialysis patients provided the participants with knowledge and information that they could compare with their own experiences.

Barry reflected on the time he spent dialysing at the hospital and the people that he met there. He was struck by how hard life was for some of them and was thankful that in comparison his experience was relatively easy:

> *There were some great people up there. I met some really nice people, elderly and everything and they've all got different stories, different ways of looking at it. …there is a gentleman there with no legs from diabetes and he gets in there in the morning 7 o'clock for his session. He doesn't get to go out of there until sometimes 8 o'clock at night. I was in the afternoon session and he'd be in there all day … That's why I say there are people worse off …*

William also acknowledged that by listening to others it was possible to gain a new perspective on his own experience.

> *You finally realise, well I never thought about it that way. You hear other people's versions of things and it opens up your mind to that aspect of it as well.*

As well as gaining perspective on their own experiences, stories from within the dialysis community also helped people maintain hope while waiting for a transplant. Cathy happily recounted the time she heard that a person she knew from the dialysis unit had received a transplant:

> *… Maria told me … she say George has got a kidney. I'm like my cross and I was crying and I say, "Good on you George", because you can say to yourself one day maybe going to be me too and somebody else might be happy.*

These data illustrate the peer support that exists between dialysis patients. Two dialysis patients are talking joyfully about a third who had got a transplant and Cathy is recognising that when she too receives her kidney, other patients will hear about her and be given hope.

Living on dialysis while waiting for a kidney transplant places new pressures and expectations upon existing relationships and leads to the development of new friendships. Connections made through the dialysis experience can provide perspective and hope, while a renewed appreciation of significant relationships can lead to deceit and disconnection as loved ones are shielded from the true impact of the disease burden and the deep desire for a transplant.

6.6 Feelings towards the deceased donor

The final theme from the data is the deceased donor who provides the kidney and thus facilitates the hoped-for return to normal life. Although there was no specific question about donors in the focus group question guide, the topic came up in both focus groups as people recalled their experiences with loved ones coming forward as potential donors. For various reasons these living donors were unable to go ahead, leaving the participants with no option but to wait for a deceased donor. Focus group participants were reluctant to dwell on the concept of someone having to die in order for them to receive their transplant. Although there was only a small amount of data, two subthemes were apparent. Firstly there is a sense of the practical logic of using organs from people who are deceased. Along with this practicality, the second subtheme is an appreciation of the human cost of the donation and the pain that the donor's family would experience in order for them to receive the transplant they desire.

6.6.1 Pragmatic appreciation

Participants rationalised their need for a deceased donor as a practical use of an organ that was no longer required. April said that in her Asian culture it was unacceptable to ask a living person to donate an organ, but for a deceased person she said:

> *That's why donation I think is good, because I believe that when the people pass away, it's not useful anymore. What's that one used for? So, if not used for things you can reuse it, help other people live. That's good.*

Barry too was comfortable with the idea of getting an organ from a deceased donor. He said:

But a donor, someone that's passed away, I can live with that, no issue at all.

This comment came during a discussion about living donors. Barry was expressing his preference to get a kidney from a deceased donor, rather than put a loved one at risk. Both April's and Barry's comments show that they believe the use of good organs from people who are deceased is a sensible alternative to taking them from healthy living people.

6.6.2 Identifying with another's loss

Mary's remarks in the same discussion shared Barry's lack of concern toward the donor but showed more insight regarding the circumstances and the other people who might be affected.

Like you say if it is a donor kidney, I'm happy to - I won't feel the guilts in a way. In the back of my mind I think I will feel bad for the family, they've lost a family member. But I don't think I will have such a big issue.

Mary said she would be happy to receive a kidney from a deceased donor without the same "guilts" she would have felt if her own family member had donated an organ. The person would have died anyway, whether or not they donated their organs, therefore Mary did not feel personally responsible for causing them harm. However her comment shows a deeper recognition of the grief of loss that the donor's family would experience. She identified with them as people who would be suffering the loss of a loved one.

Some of the participants showed they appreciated the human loss involved by not wanting any information about the donor. Cathy and April agreed that neither of them wanted to know anything about their donor.

(Cathy) … *Myself, I don't want to find out somebody died. If they got a kidney for me I don't want to know who gave it to me.*

(April) … *No one - no I don't want too … No it's better don't see people.*

Cathy struggled with the idea that when her kidney came it meant that someone somewhere had passed away:

Myself, sometimes my husband tell me don't worry you know, you're going to be lucky. I said … I'm not make my cross to God somebody to die and I get the kidney. It's not good. If I'm lucky one will just come nicely,

Cathy said that she could not pray to God for a transplant as it would be like praying for someone to die. She understood that there would not be a transplant unless someone died. She told her husband off when he said she would be lucky one day because she knew that her lucky day would be a very bad day for the donor. Instead she chose to ignore this fact and hope for a kidney to "come nicely".

Some participants struggled with emotions surrounding the death of the donor. Although using the donor's organs to help others made no difference to the outcome for the donor, participants realised that when their transplant kidney becomes available the donor's family would be grieving and suffering the loss of their loved one. Participants did not express any feelings of personal guilt for the donor's death, but wishing for the transplant to happen caused mixed emotions because it meant the death of another. They lived with the knowledge that when their longed-for transplant and escape from dialysis took place, it would be as a result of someone's death. When they finally received the call they had been waiting for, there would be a family of grieving relatives mourning the death of the donor.

6.7 Conclusion

This chapter has reported on the experience of waiting for a kidney transplant as shown in the data. The data show that living on dialysis is physically and mentally challenging, while the wait for a transplant is accepted as part of everyday life. A kidney transplant is seen as the event that will give freedom to live a normal life again. The experience of waiting is fraught with feelings of uncertainty regarding the timing and the outcome of the transplant. The dynamics of existing relationships are altered with people experiencing a fresh appreciation of the support they receive from family members, while at the same time distancing themselves in order to protect their loved ones from further worry. New supportive relationships develop within the dialysis community. Key to getting a transplant was a deceased donor with the data revealing gratitude towards the donor and an understanding of the human loss involved. In the next chapter these findings will be discussed in context with the existing literature.

CHAPTER 7 **QUALITATIVE DESCRIPTIVE STUDY: DISCUSSION**

7.1 Introduction

The aim of this qualitative descriptive study was to describe the experience of waiting for a kidney transplant from a deceased donor from the perspective of the people waiting. The data showed that participants were so immersed in the experience of living on dialysis that it was hard for them to separate their feelings about dialysis from their feelings about waiting for a transplant. Living on dialysis was an integral component of waiting for transplant that loomed large in the participant's lived experiences. Living on dialysis was the context from which all their answers came, as if they were trapped in dialysis and the kidney transplant was the means of escape. Participants did not know how long they would have to wait and they experienced both hopes and fears for life with a kidney transplant. People lived each day in a liminal state: prepared to stay, but ready to leave; enduring yet accepting; connecting and disconnecting with the people in their lives. Key to the escape was the deceased donor who would release them at a time that was unknown and outside of their control.

7.2 The all-encompassing and overwhelming nature of living with ESKD

People waiting for a kidney transplant from a deceased donor have often lived with CKD for many years prior to starting dialysis. During this time they gradually add more and more restrictions to their lives. To combat feeling short of breath when fluid overloaded, fluid intake is restricted. Faced with lethargy caused by anaemia, daily activity is reduced. As normal renal function decreases, the diet is regulated and a complex regimen of medications introduced. On commencement of dialysis, another set of restrictions is applied to an already restricted life. Surgeries take place to establish and maintain dialysis access. Large chunks of time are spent attached to the dialysis machine; three or four times a week for haemodialysis or every night for PD. Even people who dialyse independently at home invest weeks of time learning the necessary skills. On top of all this is the requirement to be available for multiple doctors' appointments and the inevitable hospital admissions during periods of crisis (Ahmad et al. 2015; Burns, Fernandez and Stephens 2015; Calvey and Mee 2011; Crabtree and Jain 2015; Daugirdas 2015).

This study has found that people who are living on dialysis with ESKD while waiting for a kidney transplant from a deceased donor are burdened by their disease and by the dialysis treatment. Although the focus of the study was about waiting for a kidney transplant, participants spoke at length about how dialysis affected their lives. They accepted that

dialysis was necessary to continue living, but they demonstrated a sense of lives lived within boundaries that had been forced upon them, with limited opportunities for travel, employment, financial independence, and normal social interaction.

This finding is consistent with the literature about living with chronic illness. Chronic conditions such as ESKD are continuous and never-ending (Stewart and Sullivan 1982), disrupting peoples' lives (Bury 1982) as they adapt to the limitations of the illness and the demands of therapy (Sheilds et al. 2015). People who are on dialysis and waiting for a kidney transplant describe a poorer quality of life than before they became ill (Alshraifeen, McCreaddie and Evans 2014; Gomez-Besteiro et al. 2004; Landreneau, Lee and Landreneau 2010). The surrender of time and autonomy to dialysis therapy results in a sense of loss and bereavement as people reflect on all the activities and pursuits they cannot continue (Calvey and Mee 2011; Monaro, Stewart and Gullick 2014; Polaschek 2000; Polaschek 2003b). Even self-identity is affected (Charmaz 1983) as people fail to maintain the kind of normal life they had always hoped to live (Bury 1982; Monaro, Stewart and Gullick 2014). The first synthesised finding of the systematic review (Burns, Fernandez and Stephens 2015) showed that people waiting for a kidney transplant from a deceased donor are deeply affected by the experience of living on dialysis, and the data from this study provides further confirmation of this view.

7.2.1 Hoping to escape dialysis with a transplant

From the perspective of a person living with ESKD, the possibility of a kidney transplant allows them to view their ongoing and irreversible chronic disease (Sav et al. 2013) more like an acute disorder, as something temporary that can be escaped from (Moran, Scott and Darbyshire 2011; Yngman-Uhlin, Fogelberg and Uhlin 2015). The hope of getting a kidney transplant one day helps people to endure and gives them a more positive outlook on life while they wait (Pierce 2014). The effect of this hope has been measured in quantitative research looking at the HRQOL scores of people with ESKD (Lin et al. 2010; Osthus et al. 2012; Santos 2011). In general HRQOL scores among people with ESKD have been found to be poorer than the general population (Alshraifeen, McCreaddie and Evans 2014). However, when comparing different groups within the ESKD population, people who are on the transplant waiting list report better HRQOL scores and less depression than those who are just on dialysis and not waiting for a transplant (Lin et al. 2010; Osthus et al. 2012; Santos 2011).

The findings of the study also confirmed that waiting for a kidney transplant gave people hope that they would not have to live on dialysis for ever. Study participants clearly articulated the hope they held that a kidney transplant would bring them freedom from dialysis. While living with the overwhelming physical and psychological burdens of dialysis, the thought of getting a kidney transplant gave them hope that one day they would live a normal life again. Even being on the waiting list was viewed as a positive, and the prospect of their name being removed from the list was mentioned with horror. The thought of dialysis as their only option was described as depressing and frightening.

7.2.2 Waiting becomes a normal part of life

Waiting for a kidney transplant has been described as a liminal experience, in-between chronic illness and transplantation (Molzahn, Bruce and Sheilds 2008). People on the waiting list for a kidney transplant are immersed in the experience of living with a chronic illness (Charmaz 1991) and endure a restricted life, often for many years (Tong et al. 2015). Chronic illness has been described as living on someone else's schedule (Mulcahy, Parry and Glover 2010) and people waiting for a kidney transplant develop a state of acceptance, acknowledging they have no influence over when a donor organ will become available (Sadala et al. 2012). Denial and distraction have been found to be effective strategies people use to manage the experience of waiting (Brown et al. 2006; Mitchell et al. 2005; Naef and Bournes 2009; Sweeny and Cavanaugh 2012).

The study found that after time, people come to accept the wait for a transplant as a normal part of life. The initial excitement when people are first placed on the transplant waiting list eventually wanes and settles into a state of acceptance. People carry on with their daily responsibilities and do not focus on the transplant. They choose not to think about the transplant, and instead they distract themselves by carrying on with their normal activities of life such as work, spending time with family and maintaining dialysis. Their use of metaphor illustrates how the wait was something they had accepted and normalised as an everyday part of life. In congruence with the literature, this study's findings demonstrate that waiting for a transplant becomes normalised and accepted as part of everyday life.

7.3 Living with uncertainty

In the literature uncertainty is often linked with the experience of waiting for a kidney transplant. The systematic review showed as well as the psychological challenges of living

with a chronic illness, waiting for a kidney transplant itself affected a person's mental wellbeing with uncertainty resulting in stress and anxiety for people who were waiting (Burns, Fernandez and Stephens 2015). The wait for a kidney transplant contains many elements that contribute to feelings of uncertainty (Pelletier 2012). The experience of living with a chronic illness such as ESKD has been described as unpredictable, with uncertainty "a continuous companion" (Sheilds et al. 2015, p. 210). The outcome of the transplant is uncertain as there is no guarantee that it will fulfil the hopes and dreams of a return to 'normal' life (Baines and Jindal 2003). Waiting itself is uncertain (Ellingsen et al. 2013; Naef and Bournes 2009) with the unknown timing of the transplant meaning that people cannot plan for the future with any confidence (Australia and New Zealand Dialysis and Transplant Registry 2015e; Tong et al. 2015).

7.3.1 An uncertain outcome

The data show that people waiting for a kidney transplant experienced fear about whether or not the transplant would be successful and free them from dialysis as they hoped. Although they focused on the positive aspects of transplantation, they understood that sometimes a transplant had serious negative consequences that could lead to them returning to dialysis or even dying. They experienced fear and uncertainty relating to the surgery, the medications, and the potential for the transplant to be lost. They also expressed their fear of being denied the opportunity to wait for a transplant. In seeking a transplant the participants hoped to return to the life they had before they became sick, free to do whatever they wanted without the restrictions of dialysis. If their hoped-for transplant failed then they knew they would have to continue the rest of their lives on dialysis. Uncertainty about the ultimate outcome of the transplant was part of the experience of waiting for a transplant.

This finding is consistent with what is known in the literature. While offering the hope of a way out, the uncertainty of waiting for a kidney transplant causes stress and anxiety (Silva et al. 2014). People try to predict when the kidney will come and whether or not the transplant will truly give them the escape they hope for (Carr, Teucher and Casson 2014; Corruble et al. 2010). The expectation that the transplant will return them to a normal life does not just bring assurance, but also anxiety and apprehension (Shih and Honey 2011; Yu and Petrini 2010). As with the participants in the study the literature reports fears relates to the possibility of something going wrong with the surgery, or of some new health problem, such as cancer, emerging afterwards as a side effect of the medication (Lasker et

al. 2010; McDermott, Hardy and McCurry 2010). Fear is also related to the prospect of losing their imagined future (Baines and Jindal 2003; Jonsén, Athlin and Suhr 2000) and facing their own mortality (Li et al. 2012).

7.3.2 An ongoing wait

In a study by Hajdarevic, Rasmussen and Hörnsten (2014), people in the initial stages of a chronic disease people felt lost and uncertain, followed by a period of "searching for solid ground" (Hadjaveric et al. 2014, p. 357). In a similar fashion, the participants of the study were keen to suggest better ways of being kept informed, to provide them with some solid ground to prepare for the future. The length of the wait for a kidney transplant can only be estimated by calculating the mean length of time that people wait (Australia and New Zealand Dialysis and Transplant Registry 2015e). Several studies have shown that people have wrongly interpreted information about the mean waiting time as the actual waiting time and have been very disappointed when the length of their wait exceeds it (Moran, Scott and Darbyshire 2011; Yngman-Uhlin, Fogelberg and Uhlin 2015). Providing people with information while they wait has been shown to both reduce uncertainty thereby lessening anxiety and frustration (Cheng and Tsai 2014; Guenter, Hetty van Emmerik and Schreurs 2014) and also in certain circumstances, be a source of increased stress (Stone et al. 2013). In the case of waiting for a kidney transplant the length of the wait cannot be predicted in clock time, therefore it is not possible to relieve uncertainty about the timing by providing information about how long the wait will last.

During the focus groups participants spoke about the difficulty of living with uncertainty. They were keen to have more information about the timing of the transplant so that they could plan for the future, but they also recognised that such knowledge could potentially be a source of stress and disappointment. For example, if they knew they were close to getting a call but then didn't get one quickly, the wait would be even more excruciating. Or if they were told that they would not get a transplant for many years, they could lose hope and become demoralized. Although information about the prospective length of the wait can help give people a better sense of control while waiting (Cheng and Tsai 2014), this is an example of how the sharing of information causes stress to increase (Stone et al. 2013).

People waiting for a kidney transplant should be provided with as much information as possible while they wait. Given the imprecise nature of the allocation process, information about the mean length of time that people wait is of limited value in reducing uncertainty. Other information such as details about the surgery and what they should expect to happen

when the call comes may have some value in reducing the effect of uncertainty while people wait (King, Dan and Johnstone 2006; Weems and Patterson 1989).

7.4 Changing relationships: connecting and disconnecting

The literature and the study findings make reference to how the experience of waiting for a kidney transplant impacts both positively and negatively on a person's relationships. People welcome the support of friends and family while at the same time try to protect them from the full impact of the disease. They feel isolated, but develop new friendships from within the dialysis community. The dynamics of existing and future relationships are altered by the experience of waiting for a kidney transplant.

7.4.1 Strengthened connections

The data show how study participants experience a fresh appreciation of the importance of their family members while they live on dialysis and wait for a transplant. By enabling them to endure the day to day challenges of life on dialysis the families are described as a "driving force", a "support mechanism" and as the reason they continue with dialysis. Study data shows that love and encouragement from families was an important source of strength for people waiting for a kidney transplant.

The systematic review also found that people waiting for a kidney transplant appreciate being part of a community and place value on relationships with family and friends (Burns, Fernandez and Stephens 2015). While living with chronic illness, including ESKD, people re-evaluate their priorities in life and place more value on relationships than they did before they were unwell (Bennett et al. 2013; Rasmussen and Elverdam 2007). Families and relationships are seen as a source of strength and encouragement that help people to endure the wait for a transplant (Monaro, Stewart and Gullick 2014; Polaschek 2000; Tong et al. 2009).

As well as appreciating the support of their friends and family members, people also develop new connections within the dialysis community which develop into valued alliances. From the diagnosis of CKD, to starting dialysis and joining the transplant waiting list, people have contact with numerous medical practitioners, nursing staff, technicians, and support staff as well as other people with ESKD. Regular communication with the medical community has been shown to reduce anxiety while people wait (Yngman-Uhlin, Fogelberg and Uhlin 2015; Yorke and Cameron-Traub 2008) while people who have little interaction with their caring physicians report feeling frustrated and forgotten (Brown et al.

2006; Jonsén, Athlin and Suhr 2000; Yngman-Uhlin, Fogelberg and Uhlin 2015). Each member of the medical community imparts information which has an impact on the overall experience of waiting for a transplant (Wehrens 2014). Likewise, meeting with other people who are waiting or who have received kidney transplants can be beneficial. People can learn from the stories of others who have endured the same situation and be encouraged that they are not alone (Mulcahy, Parry and Glover 2010). Information enables people to cope better with the experience of waiting for a kidney transplant (Calvey and Mee 2011) although facts gained from other dialysis patients may be out of date and inaccurate (Landreneau, Lee and Landreneau 2010).

The data show that participants value their relationships with other people who were living on dialysis or who had received a kidney transplant. While the literature says a lot about the beneficial effect of contact with the health care team, this study found that participants spoke more about the other patients that they knew, rather than any of the staff they encountered. They watched and listened to the people around them and learned from the experiences of others. Throughout the data, participants referred not just to their own experiences, but also to the experiences of other people they had met while on dialysis. The stories of these others were reported along with their own, and provided a reference framework to compare their own experiences with.

7.4.2 Protective isolation

The literature has described how people living with a chronic disease such as ESKD may feel socially isolated (Bonner, Wellard and Caltabiano 2010; Herlin and Wann-Hansson 2010; Kuluski et al. 2014; Polaschek 2000) and a burden to their loved ones (Calvey and Mee 2011; Yngman-Uhlin, Fogelberg and Uhlin 2015). Michael (1996) reported that people with a chronic illness felt a “loss of connectedness” and found it difficult to relate to others as they had done prior to their diagnosis (Michael 1996, p. 256). A lack of common experience made it difficult for people to relate to each other as they had done before the diagnosis of a chronic disease (Michael 1996). As well as the restrictions of the actual illness, treatment of the condition has also been described as punishing, taking away precious time and affecting not only the person with the disease but their family and friends too (Sav et al., 2013).

In some cases friends and family may become intolerant towards a person with a chronic disease when they continue to have the same problems and fail to get well (Bury 1982; Stewart and Sullivan 1982). People with a chronic condition sometimes hide the true

extent of their symptoms or emotions in order not to be a burden and to protect their loved ones from worrying about them (Jowsey, Ward and Gardner 2013; Stephens, McKenzie and Jordens 2014). This withholding of information in order not to burden others is a form of self-isolation (Monaro, Stewart and Gullick 2014; Öhman, Söderberg and Lundman 2003; Tong et al. 2009) that results in people living restricted and socially isolated lives (Charmaz 1983, P. 168).

Study data showed that participants' lives had been altered by ESKD and dialysis, meaning that they could no longer relate to their friends as they had before they were ill. They lacked available time and energy to invest in relationships, because of the hours they had to spend on dialysis therapy, and they lacked common experiences as their lives were now taken up with managing their ESKD.

As described in the literature, the data also show that as well as appreciating their family's support, the study participants hid their true feelings from their loved ones because they did not want to burden them with all the details of their illness. Every participant in the study had an example of a time they had lied or suppressed their feelings in order to prevent their family members worrying about them. For some people that meant pretending they were well when their symptoms were bad. For others it meant hiding their relief when family members were found to be unsuitable to proceed as live donors. Participants hid the truth about how they were feeling to protect their loved ones and by doing so they isolated themselves further.

7.5 Dealing with the deceased donor

For people who are on the waiting list, the transplant they are waiting for will only happen when someone dies. Not only will someone have to die, but they will have to die in a specific set of circumstances; with a compatible blood group and tissue type; willing to donate their organs; and whose family allow the donation to take place. The longed-for transplant happens at the expense of another person's tragedy and involves a series of events that cannot be predicted and can hardly be hoped for. People on the waiting list for a kidney transplant from a deceased donor are powerless to make the transplant happen more quickly and so they just wait and wish for the unthinkable.

7.5.1 A practical solution with a high human cost

The literature shows that people waiting for a kidney transplant are aware of the paradox of needing someone else to die so that they can live (Calvey and Mee 2011; Tong et al.

2015). It has been noted that there is a culture of not discussing death within the dialysis setting (Sheilds et al. 2015) and fear of their own death has been cited as one of the reasons for increased anxiety in people with ESKD (Li et al. 2012; Silva et al. 2014). Linked with the experience of facing their own mortality, people waiting for a kidney transplant understand that their transplant will only occur if somebody else dies.

While it may be sensible to talk in abstract terms about using good organs from a donor who is deceased in order to benefit others, when people are faced with the thought of who that donor actually is, where they live, work and who their families are, it is more difficult to accept. Wishing for a transplant becomes wishing for someone to die. Studies have described the "moral guilt" experienced by people waiting for a kidney transplant (Tong et al. 2015, p. 771) where transplant recipients feel responsible for the donor's death and worry that their survival is at the donor's expense (Sanner 2003). Grief reactions associated with survivor guilt have been observed among organ transplant recipients (Baines and Jindal 2003).

The findings of this study captured both the practicality of using organs from people who are deceased, along with the sense of regret towards the donor and their family. Discussion about the deceased donor was limited and where comments were made the subject was not explored, seeming to confirm the literature which noted a culture of not discussing death within a dialysis setting. Unlike the literature, none of the participants specifically expressed gratitude or guilt towards the donor. Instead there was a sense that if the donor did not need their organs anymore because they were dead, then it was logical to pass on those organs to people who needed them.

Despite their pragmatism several comments revealed that the study participants identified with the donor family's loss. Participants stated they did not feel guilty, but they felt bad for the family of the donor who would be suffering the grief of the loss of their loved one. One participant said she could not pray for someone to die so that she could get the kidney. Instead she practised denial by hoping if she was lucky one would "come nicely". It is a sad fact of transplantation that deceased donor organs do not come "nicely" but always involve a death.

This study highlights the need for a flexible approach towards providing care for people who struggle with the thought of the human cost of transplantation. In Australia there are guidelines that protect the anonymity of the donor and recipients (Transplantation Society of Australia and New Zealand (TSANZ) 2016). Schemes exist that allow recipients to write

and thank their donor's family after the transplant if they wish to (Donatelife 2014), but there is nothing in place for people while they are waiting. The uncertainty surrounding the circumstances of the donor would make formal pre-transplant communication impossible, but there may be a place for psychological care to relieve anxiety in individuals who find the idea difficult to live with (Sheilds et al. 2015; Silva et al. 2014).

The experience of waiting for a kidney transplant ends with the death of a donor. For the group of people waiting for a kidney transplant, death is both the problem they are seeking to avoid, and the solution that they anxiously await. While avoiding death by living on dialysis they hope for a transplant that can only come about by the death of a donor.

7.6 Conclusion

This study has found that the experience of waiting for a kidney transplant takes place within the context of life on dialysis which is the over-riding concern for people in this population. The thought of receiving a kidney transplant gives people hope of one day escaping from dialysis and returning to 'normal' life with the freedom to work, travel and relate to people as they did before dialysis (Calvey and Mee 2011; Dekkers, Uerz and Wils 2005; Hagren et al. 2001; Herlin and Wann-Hansson 2010; Moran 2008; Polaschek 2000; Rittman et al. 1993; Sadala et al. 2012).

Waiting for a kidney transplant involves living with uncertainty, not knowing how long the wait will be or whether the transplant will result in the hoped for recovery (Calvey and Mee 2011; Hagren et al. 2001; Herlin and Wann-Hansson 2010; Kaba et al. 2007; Moran 2008; Pelletier 2012; Polaschek 2000). People fear they may never get a transplant or that something will go wrong with the transplant when it happens (Bjork and Naden 2008; Jonsén, Athlin and Suhr 2000; Shih and Honey 2011; Yu and Petrini 2010). Underlying all these fears is the dread of life on dialysis without the hope of any escape (Baines and Jindal 2003; Yngman-Uhlin, Fogelberg and Uhlin 2015).

Waiting time can be estimated in clock time, but is actually experienced as an embodied and liminal experience, to be endured for as long as it takes; in between illness and health (Kierans 2005; Molzahn, Bruce and Sheilds 2008). People who are waiting for a kidney transplant reconstruct their use of time and place greater value on relationships and activities that are important to them (Bennett et al. 2013; Yngman-Uhlin, Fogelberg and Uhlin 2015). Support from other people (Brown et al. 2006; Jonsén, Athlin and Suhr 2000; Polaschek 2003b; Scott et al. 2011; Yorke and Cameron-Traub 2008); the acquisition of

knowledge (Stone et al. 2013); denial (Brown et al. 2006); and distraction (Naef and Bournes 2009) are strategies that people use to help them endure the wait.

The key to getting a kidney transplant is a deceased donor. It is an ironical fact that peoples' efforts to avoid mortality by seeking a transplant are only achieved by the death of another (Calvey and Mee 2011; Tong et al. 2015). Feelings towards the deceased donor may include gratitude and guilt (Baines and Jindal 2003; Li et al. 2012; Sanner 2003; Silva et al. 2014), although the results of this study showed a sense of pragmatism combined with concern for the donor's family.

7.7 Strengths of the study

The study provides information about a significant patient population which few previous studies have specifically investigated, thereby helping to fill a gap in the literature. Purposive sampling was used to ensure the participants were appropriate to comment on the experience of waiting for a transplant from a deceased donor. The sample included both male and female participants of varying ages and from a diverse range of cultural and professional backgrounds. People who are living on dialysis are a time poor population with a commitment of at least 15 hours per week to their dialysis therapy on top of family commitments, work and medical appointments. By scheduling the focus groups on different days of the week and different times of day, the number of people on in-centre or satellite haemodialysis who were able to attend was maximized. Audio-recording of the focus groups followed by verbatim transcription of the recordings enhanced the credibility and authenticity of the data (Polit and Beck 2014). The use of dual moderators in the focus groups ensured that the novice researcher was supported while leading a focus group for the first time, and allowed for all the needs of the participants to be met and all lines of discussion to be fully explored (Kamberelis and Dimitriadis 2011). Participants showed they felt free to express a range of opinions by discussing both positive and negative outcomes of waiting for a transplant.

7.8 Limitations of the study

The main limitation of this study is the small sample size and the fact that it was a convenience sample made up of participants from one metropolitan hospital in Sydney, Australia. Although data saturation was reached within this group, new findings may become apparent if the study were repeated with a larger sample size or with people under the care of another hospital or in another state or country. The experience of waiting for a

kidney transplant may vary depending on the resources that people have available to them. For this reason these findings of this study cannot be said to be generalizable.

7.9 What does this study add to the existing literature?

The findings of this study have highlighted several areas that contribute to existing literature about waiting for a kidney transplant.

- People who are waiting for a kidney transplant from a deceased donor accept the wait as a normal part of daily life. The restrictions of living on dialysis have more impact on day-to-day living than the experience of waiting for a transplant.
- The feelings of uncertainty experienced by people who are waiting for a kidney transplant relate to the timing of the transplant, and also whether or not it will be successful and give them the freedom to live a normal life.
- Social relationships are highly valued by people waiting for a transplant. They experience a renewed appreciation for the practical and emotional support of loved ones, but they also deliberately shield those people from the details of their disease so as not to cause excessive worry and concern.
- People who are waiting for a kidney transplant learn from the stories and experiences of their peers in the dialysis community.
- People who are waiting for a kidney transplant do not dwell on the situation of the donor because it is difficult to live with needing another person to die.

7.10 Recommendations

The findings of this study suggest several areas for further research:

- What interventions are effective to support people while they wait for a kidney transplant from a deceased donor? Specific areas which people may need assistance with include: living well with a chronic illness, psychological support to endure an indefinite wait, help with processing the concept of receiving an organ from a deceased person.
- Given that the experience of waiting can be improved by good communication and the provision of information (Cheng and Tsai 2014; Guenter, Hetty van Emmerik and Schreurs 2014) how can people best be kept informed while waiting for a transplant? The effectiveness of print and lecture based methods of imparting information could be assessed and alternative methods of communication, such as

story based, visual resources could be developed to cater for non-readers and people from different cultural and linguistic groups.

- What are the most effective ways of supporting the development of therapeutically beneficial relationships within the community of family, friends, health care providers and fellow patients? Possible interventions may include the use of social media to connect people with each other, newsletters incorporating patient stories and support groups.
- The existing qualitative study could be repeated across multiple centres internationally to see whether any new findings emerge in different settings. Larger sample sizes may be achieved by adopting a method of data collection that is more accessible to members of the dialysis population such as individual interviews or through the use of social media (Lunnay et al. 2015).

CHAPTER 8 **CONCLUSION TO THE THESIS**

The aim of this thesis is to provide an account of what day-to-day life is like for people who are living on dialysis while waiting for a kidney transplant from a deceased donor. This question is significant because it is estimated that over 170 000 people are waiting for a kidney transplant worldwide (Australia and New Zealand Dialysis and Transplant Registry 2015a; Council of Europe 2014; NHS Blood and Transplant 2015; United States Renal Data System 2014a). Donor organs are allocated to recipients by a computer algorithm that prioritises good tissue type matching over the length of time spent waiting, meaning that it is possible for people to get a kidney transplant after waiting only a short time. It is impossible to predict when a person will receive an offer as it depends on variable factors such as the blood group and tissue typing of the donor organ and the compatibility of everyone else on the list at the time.

A wide ranging literature review was conducted to inform the study, referring to literature describing the experience of living with chronic illness; the passage of time; the experience of waiting; and the concept of uncertainty. It included qualitative and quantitative studies looking at the experience of waiting for different kinds of solid organ transplants such as liver, lungs and hearts. Themes within this literature include waiting for a kidney transplant may cause people to feel high levels of stress and anxiety (Li et al. 2012; Santos 2011; Shih and Honey 2011; Yu and Petrini 2010). This may be due to uncertainty about when the kidney transplant will come, concerns about whether the kidney transplant will work and because of feelings of guilt towards the donor who will have to die in order for the transplant to take place (Baines and Jindal 2003). The literature indicates that feelings of anxiety and frustration while waiting may be reduced by good communication and by the provision of information regarding the wait (Cheng and Tsai 2014; Guenter, Hetty van Emmerik and Schreurs 2014). In the case of waiting for a kidney transplant information about the length of the wait is not available, although good communication may relieve anxiety in this population (King, Dan and Johnstone 2006; Weems and Patterson 1989).

Following the general literature review, a systematic review of the qualitative literature was undertaken, focusing on papers that described the experience of waiting for a kidney transplant (Burns, Fernandez and Stephens 2015). Twelve studies were found for inclusion in the systematic review, and of those most were designed to examine the experience of living on dialysis with the experience of waiting for a kidney transplant reported incidentally. The systematic review made three findings. Firstly, people who are waiting

for a kidney transplant from a deceased donor are affected by the experience of living on dialysis with ESKD and its impact on their physical health and normal activities of living. Secondly, the experience of waiting for a kidney transplant from a deceased donor impacts a person's psychological wellbeing. Thirdly, people who are waiting for a kidney transplant from a deceased donor place value on relationships and being part of a community.

Having established what is already reported about the experience of waiting for a kidney transplant in the literature, it became apparent that there was a gap in the knowledge for a study specifically designed to investigate that exact experience. A qualitative descriptive study was conducted using focus groups to collect data from a purposive sample of patients based at one metropolitan hospital in southern Sydney. Thematic analysis of the data identified four main themes, each with subthemes that described the experience of waiting for a kidney transplant from a deceased donor.

Firstly people who are waiting for a kidney transplant view the transplant as a means of escape from the restrictions of their life on dialysis. The hope of getting a transplant one day is widely reported in the literature, but in this study it was also noted that the actual wait becomes accepted as a normal part of daily life with dialysis the greatest cause of concern to participants.

Secondly people who are waiting for a kidney transplant live with uncertainty. This has been reported in other studies (Moran, Scott and Darbyshire 2011; Silva et al. 2014) and relates to both the uncertainty around the timing of the transplant and uncertainty about whether the transplant will work or not. There is fear about the kidney failing and about being left with no option in life other that dialysis.

Thirdly, the experience of waiting for a kidney transplant alters a person's relationships with the people around them. People waiting for a kidney transplant value those who give them help and encouragement, but also try to protect them from the full impact of the disease by downplaying the true extent of their symptoms and emotions. People who are waiting for a kidney transplant find it hard to relate to people they knew before they started dialysis because of the disparity in life experience, but the data show that they enjoy developing new friendships from within the dialysis community and learn from the experiences of others. The importance of relationships has been mentioned in the literature (Bennett et al. 2013; Monaro, Stewart and Gullick 2014) but the complex nature of connection with some people and disconnection from others, and the best way to utilise relationships in order to support people who are waiting.

Finally, people waiting for a kidney transplant experience complex emotions towards the deceased donor. While on one level they strongly hope that an organ from a person who is deceased will become available quickly, they also appreciate the great cost to that person and their family. Wishing for a transplant is like wishing for someone to die.

8.1 Limitations of the thesis

The individual elements within the thesis each had limitations. In the systematic review only two of the twelve included studies specifically stated that all the participants were waiting for a transplant. In the qualitative descriptive study only six of a potential 29 participants attended the focus groups and they were all patients of one metropolitan hospital. With the requirement to invest time in dialysis therapy on top of their existing commitments to family, employers and medical care, this group of people has limited spare time to attend extra appointments such as focus groups. As a difficult group of people to reach this may explain why there is a lack of studies specifically relating to waiting for a transplant. Future research with this group of people may benefit by considering the use of a more participant centred method of data collection such as individual interviews in the home or during dialysis session. Repeating this research in different settings and different countries, may also provide different insights.

8.2 Implications for practice

The findings of the systematic review and the qualitative descriptive study have implications for the nurses who care for people who are waiting for a kidney transplant. Both the review and the study found that living on dialysis while waiting for a kidney transplant is physically and psychologically demanding. This knowledge helps nurses working with this group of people and would suggest that every effort be made not to add to their therapeutic burden by the unnecessary scheduling of tests and appointments. Recognising that people experience a combination of both hope and fear while they wait calls for nurses to be sensitive. For example, an angry response to being made interim on the list for a time may seem inappropriate, but the thesis findings would suggest that people may perceive that their hope is being taken away. Similarly people's reluctance to attend appointments or keep testing up to date may indicate fear about transplantation itself.

The findings of the review and the study have both shown that waiting for a transplant affects a person's relationships. Supportive relationships are highly valued in this group

and may come from new directions such as within the dialysis community itself. Nurses and other staff within the renal department should not only be sources of support themselves, but should also find ways to facilitate connection with others in the same situation.

For some people on the waiting list the thought of waiting for a donor to die is difficult. Nurses should be able to provide people with information about the process of deceased donation in order to answer any questions or concerns a person may have, but this should be requested by the person as individual concerns vary.

By identifying these themes and discussing them in the light of what is known in the literature, this study provides a descriptive summary of what it feels like to wait for a kidney transplant from a deceased donor from the perspective of the person waiting. The descriptive summary and the systematic review of the literature are combined in this thesis to contribute to what is known about the experience of waiting for a kidney transplant from a deceased donor.

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APPENDIX 1: COMPARISON OF RENAL REPLACEMENT THERAPY MODALITIES

Mortality	
Dialysis	13.1% (per 100 patient years) (Australia and New Zealand Dialysis and Transplant Registry 2015b)
Kidney transplant	2.3% (per 100 patient years) (Australia and New Zealand Dialysis and Transplant Registry 2015b)
Technique survival	
Haemodialysis	53% patient survival at 5 years, censored for transplant but not for patient death (Australia and New Zealand Dialysis and Transplant Registry 2015c)
Peritoneal dialysis	21% technique survival at 5 years (Australia and New Zealand Dialysis and Transplant Registry 2015d)
Kidney transplant	81% graft survival rate at 5 years after receiving a kidney transplant from a deceased donor (Australia and New Zealand Dialysis and Transplant Registry 2015f)
Physiological challenges	
Haemodialysis	Shifts in fluid volume and changes to electrolyte concentrations during HD sessions can be difficult to tolerate and cause symptoms such as hypotension, headaches, nausea and loss of consciousness (Chao, Huang and Yen 2015; Pietribiasi et al. 2015).
Peritoneal dialysis	Physiological challenges of PD include mechanical complications such as hernia formation, dialysate leak, genital oedema and respiratory problems; and metabolic complications such as impaired glucose and lipid absorption and the gradual erosion of the peritoneal membrane (Blake and Daugirdas 2015).
Kidney transplant	The physiological challenges of transplantation relate to rejection of the transplanted organ, recurrence of the original disease in the new organ and the side effects of immunosuppressive medication. Rejection can be treated with immunosuppressive medication and does not always lead to the loss of the transplanted organ (Burton et al. 2015; Lo, Kaplan and Kirk 2014). Hyper-acute reaction occurs within hours of the surgery and is an emergency situation requiring immediate removal of the

	graft. Acute rejection is also of sudden onset while chronic rejection develops more slowly over months or years. Australian data shows that hyper-acute rejection accounts for <1% of graft losses whereas acute rejection occurs in 16% of transplants although it only causes 3.2% of graft losses (Australia and New Zealand Dialysis and Transplant Registry 2015f). Graft loss due to disease recurrence depends upon the original disease (Delville et al. 2014; Henderson and O'Connell 2014). Not all causes of kidney failure recur, and diseases that cause progressive damage over a prolonged period of time such as diabetes and hypertension are more strictly controlled after transplant to limit damage to the new organ. It has been estimated that up to 30% people with an original kidney disease of a recurring type experience graft loss within 5-10 years (Floege et al. 2014). Immunosuppressive medication, while essential to prevent rejection in the grafted organ, is associated with a range of long term complications and comorbidities. Incidence of all types of cancer in people who receive kidney transplants is around 14%, approximately double that of the general population (Wong, Germaine et al. 2013). Cardiovascular disease accounts for approximately 25% of kidney transplant recipient deaths in Australia and 40% in New Zealand (Farrugia et al. 2014; McDonald 2013). New-onset diabetes after transplant (NODAT) is a metabolic disorder believed to be related to the use of immunosuppressive medication which also affects post-transplant graft survival and mortality (Sarno, Muscogiuri and De Rosa 2012).
Surgical challenges	
Haemodialysis	Surgical challenges of haemodialysis relate to the maintenance of a functioning vascular access such as stenosis, infection or aneurysm (Rose, Sonaike and Hughes 2013).
Peritoneal dialysis	The insertion of a permanent PD catheter into the abdomen may take place under general or local anaesthesia. Complications include infection and bowel perforation (Blake and Daugirdas 2015).
Kidney transplant	Kidney transplantation involves major surgery. Surgical complications include delayed wound healing (Fockens et al. 2015) and leaking, blockage

	(thrombosis), narrowing (stenosis) or breakdown (necrosis) of any of the joins in the blood vessels or ureters (Lempinen et al. 2015). Surgical complications occur in up to 10% of cases (Bessede et al. 2012; Lentine et al. 2014; Naesens et al. 2013; Saeb-Parsy et al. 2010; Ziętek et al. 2007).
Procedural challenges	
Haemodialysis	Each dialysis session two cannulas are inserted into the fistula or graft to remove and return the blood. Dialysis cannulas are large, usually 14-15 gauge, in order to accommodate the high blood flow rate required to facilitate the cleaning of large blood volumes (Parisotto et al. 2014). Technical problems relating to the blood circuit include pain and difficulty cannulating, clotting of the blood lines, and needle displacement resulting in air embolus or haemorrhage (Tennankore et al. 2015). People on home HD are trained to manage every aspect of their treatment independently including operating the HD machine, inserting the HD cannulas into their own fistulas and troubleshooting any medical or technical issues (Rajkomar et al. 2014).
Peritoneal dialysis	The maintenance of strict asepsis during connection to the PD machine is essential to prevent exit site infection and peritonitis (Blake and Daugirdas 2015).
Mechanical challenges	
Haemodialysis	Haemodialysis machines consist of a pump and a filter containing the dialysis membrane. The technology is constantly improving with online fluid monitoring, sodium and bicarbonate profiling and haemodiafiltration available to individualise treatment and optimise the clearance of waste products (Blankestijn 2013; Karkar 2012; McCausland, Brunelli and Waikar 2013). Problems may occur with the machine, the electricity and water supplies or with faulty dialysis products (Farrington and Greenwood 2011).
Peritoneal dialysis	Peritoneal dialysis is less complex than the HD and is offered as a home rather than a hospital based therapy. Those choosing to carry out automated PD (APD) at night must master the operation of the machine with phone support available to trouble-shoot (Blake and Daugirdas 2015). As with HD, problems may occur with the machine, dialysis products, water or power supplies.
Infection risk	

Haemodialysis	Infection is a significant problem in all RRT options (McDonald 2013) but higher infection rates have been found to exist in people on dialysis possibly due to the continuous use of invasive procedures or indwelling devices (Bedendo et al. 2011).
Peritoneal dialysis	The most common complications of PD are infective including exit site infections at the point where the PD catheter protrudes from the skin, and peritonitis (Ellam and Wilkie 2011; Klarić and Knotek 2013).
Kidney transplant	Transplant recipients show higher rates of infection than the general population (Kyle 2014) while certain uncommon infections such as cytomegalovirus (CMV) (Helanterä et al. 2014), BK virus (Pham, Schaenman and Pham 2014) and pneumocystis jirovecii pneumonia (PJP) (Chen et al. 2014) cause very serious illness, graft loss and death within the transplant population.
Lifestyle	
Haemodialysis	People spend a minimum of 12 hours per week connected to the HD machine either at a hospital or satellite dialysis centre, or independently at home (Caring for Australasians with Renal Impairment 2005b; Hakim and Saha 2014). In addition to the time attached to the dialysis machine, people who have HD at a hospital or satellite unit have to add on travel time to the dialysis unit and waiting time to get connected to the machine (Moist et al. 2008; Moran 2008). Life on HD has been described as a restricted or a 'lost' life with the loss of spontaneity and of the person's ability to contribute to family and community (Clarkson and Robinson 2010; Monaro, Stewart and Gullick 2014).
Peritoneal dialysis	Peritoneal dialysis is most commonly carried out overnight using an APD machine allowing people freedom to carry on with normal activities during the daytime. Occasionally people prefer continuous ambulatory peritoneal dialysis (CAPD) where manual exchanges are performed throughout the day (Bieber et al. 2014; Hakim and Saha 2014).
Kidney transplant	Without the time constraints of dialysis therapy, people with functioning kidney transplants are more able to pursue employment and other activities (Murray et al. 2014). Fatigue and activity levels are reportedly similar in people with CKD pre-dialysis, on HD and on PD, while renal transplant

	recipients report the least fatigue (Artom et al. 2014; Bonner, Wellard and Caltabiano 2010).
Quality of life	
Dialysis	Quality of life studies have found that people on dialysis show higher levels of anxiety and depression than the general population (Alavi, Aliakbarzadeh and Sharifi 2009; von der Lippe et al. 2014). In a study of HRQOL in 72 people on HD in Scotland, Alshraifeen, McCreaddie and Evans (2014) found that people receiving HD therapy scored lower than the general population in all domains (Alshraifeen, McCreaddie and Evans 2014).
Kidney transplant	Studies have found that people with a functioning kidney transplant report a better QOL than those on dialysis (Alavi, Aliakbarzadeh and Sharifi 2009; Alvares et al. 2012; Landreneau, Lee and Landreneau 2010; von der Lippe et al. 2014; Wyld et al. 2012).
Cost of treatment	
Dialysis	The costs associated with dialysis include paying for staff such as nephrologists, nurses and technicians; the technology, power and consumables, and the indirectly related costs of hospital admissions and transport (Cleemput and De Laet 2013; Karopadi et al. 2013). Using data from the UK Renal Registry an economic analysis of the cost of CKD in the UK was carried out and found that the annual cost of a kidney transplant was £14618 per patient, while the cost of HD was £24043 and PD £20078 (Kerr et al. 2012). These findings have since been confirmed in studies from around the world: hospital HD is the most expensive RRT option while the home dialysis options of PD and home HD are cheaper.
Kidney transplant	As well as staff and admission costs, transplantation also involves the cost of surgery and the ongoing expense of medications (Kerr et al. 2012). After the first 12 months transplant is the cheapest RRT option (Garcia et al. 2013; Haller et al. 2011; Rocha et al. 2012; van Holder, van Biesen and Lameire 2014). It has been noted that savings made with kidney transplantation are dependent on the quality and longevity of the transplanted organs. In recent years the donor pool has been increased by accepting extended criteria donors and these organs can be more expensive in the short term as more medical and

	surgical interventions may be required to get them transplanted and working successfully. They may also have a shorter survival time which will add to the overall financial cost of kidney transplantation (Axelrod 2013).

APPENDIX 2: SYSTEMATIC REVIEW SEARCH STRATEGIES

Medline search strategy

1. kidney failure.mp. or exp Renal Insufficiency/
2. peritoneal dialysis.mp. or exp Peritoneal Dialysis/
3. kidney transplantation.mp. or exp Kidney Transplantation/
4. Kidney Failure, Chronic/ or Renal Dialysis/ or haemodialysis.mp. or Kidney Diseases/
5. renal dialysis.mp. or exp Renal Dialysis/
6. waiting list.mp. or exp Waiting Lists/
7. (tissue and organ procurement).mp. [mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]
8. quality of life.mp. or exp "Quality of Life"/
9. experienc$.mp. or Social Support/ or Depression/
10. adaptation.mp. or Adaptation, Psychological/ or Adaptation, Physiological/
11. Attitude to Health/ or Attitude/ or Attitude to Death/ or attitude.mp.
12. uncertainty.mp. or exp Uncertainty/
13. life change events.mp. or exp Life Change Events/
14. self care.mp. or exp Self Care/
15. self concept.mp. or exp Self Concept/
16. self efficacy.mp. or exp Self Efficacy/
17. interpersonal relations.mp. or exp Interpersonal Relations/
18. activities of daily living.mp. or exp "Activities of Daily Living"/
19. 1 or 2 or 3 or 4 or 5 or 6
20. 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18
21. 19 and 20
22. limit 21 to (english language and humans and "all adult (19 plus years)")
23. limit 22 to ("qualitative (maximizes sensitivity)" or "qualitative (maximizes specificity)" or "qualitative (best balance of sensitivity and specificity)")

Embase search strategy

1. kidney failure.mp. or exp kidney failure/
2. peritoneal dialysis.mp. or exp peritoneal dialysis/
3. kidney transplant$.mp. or exp kidney graft/
4. kidney failure.mp. or exp kidney failure/
5. renal dialysis.mp. or exp renal replacement therapy/
6. waiting list.mp. or exp hospital admission/
7. quality of life.mp. or exp "quality of life"/
8. society/ or experienc$.mp. or follow up/
9. local adaptation/ or social adaptation/ or adaptation/ or adaptation.mp.
10. attitude to sexuality/ or social attitude/ or attitude to illness/ or attitude to death/ or attitude.mp. or attitude to health/ or attitude to life/ or attitude/ or attitude to change/ or attitude to disability/ or patient attitude/
11. Mishel Uncertainty in Illness Scale/ or uncertainty.mp. or uncertainty/ or Mishel Uncertainty in Illness Theory/
12. life change events.mp. or exp life event/
13. self care.mp. or exp self care/
14. self concept.mp. or exp self concept/
15. self efficacy.mp. or exp self concept/
16. interpersonal relations.mp. or exp human relation/
17. activities of daily living.mp. or exp daily life activity/
18. 1 or 2 or 3 or 4 or 5 or 6
19. 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17
20. 18 and 19
21. limit 20 to (human and English language and adult <18 to 64 years>)
22. limit 21 to ("qualitative (maximizes sensitivity)" or "qualitative (maximizes specificity)" or "qualitative (best balance of sensitivity and specificity)")

8.3

PsycINFO search strategy

1 exp "activities of daily living"/
2 ("activities of daily living" or ADL).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
3 exp Behavior/
4 (behavior* or behaviour*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
5 exp Cognition/
6 cognition.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
7 exp affective disorders/
8 mood*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
9 exp "Quality of Life"/
10 ("quality of life" or qol).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
11 exp interpersonal relationships/
12 "interpersonal relation*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
13 "social interaction*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
14 "social support*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
15 (wellbeing or "well being").mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
16 exp satisfaction/
17 exp Client Satisfaction/
18 satisfaction.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
19 stress*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
20 depress*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
21 exp adjustment/
22 psycholog*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
23 exp Emotions/
24 emotion*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
25 anxi*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
26 exp Lifestyle/
27 ("life style" or lifestyle*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
28 exp Uncertainty/

29 uncertaint*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
30 exp death attitudes/
31 exp Health Attitudes/
32 attitude.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
33 experience*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
34 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33
35 exp organ transplantation/
36 ((kidney* or renal) and (transplant* or donor* or provider* or survivor*)).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
37 35 or 36
38 cadaveric.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
39 37 and 38
40 (kidney* or renal).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
41 35 or 40
42 exp tissue donation/
43 "unrelated donor*".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
44 42 or 43
45 41 and 44
46 39 or 45
47 exp kidney diseases/
48 ("renal replacement therap*" or RRT or "dialysis patient*").mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
49 ((renal or kidney*) and dialysis).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
50 hemodiafiltration.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
51 (hemodialysis or HD).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
52 ("peritoneal dialysis" or PD).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
53 hemofiltration.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
54 47 or 48 or 49 or 50 or 51 or 52 or 53
55 "kidney failure".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
56 ("end stage renal" or "end-stage renal" or ESRF or ESRD).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
57 "chronic kidney".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
58 55 or 56 or 57
59 54 or 58
60 34 and 37 and 59
61 ("300" or "320" or "340" or "360" or "380" or "390").ag.
62 60 and 61

Cochrane Library search strategy

1	MeSH descriptor: [Activities of Daily Living] explode all trees	3488
2	"activities of daily living" or ADL	5596
3	MeSH descriptor: [Behavior] explode all trees	43674
4	behavior* or behaviour*	46843
5	MeSH descriptor: [Cognition] explode all trees	6160
6	cogniti*	25934
7	MeSH descriptor: [Mood Disorders] explode all trees	8381
8	mood*	8900
9	MeSH descriptor: [Quality of Life] explode all trees	13007
10	"quality of life" or qol	31258
11	MeSH descriptor: [Interpersonal Relations] explode all trees	3707
12	"interpersonal relation*"	1603
13	"social interaction*"	672
14	"social support*"	3413
15	wellbeing or "well being"	5477
16	MeSH descriptor: [Personal Satisfaction] explode all trees	373
17	MeSH descriptor: [Patient Satisfaction] explode all trees	7896
18	satisfaction	17684
19	stress*	21813
20	depress*	52675
21	MeSH descriptor: [Adaptation, Psychological] explode all trees	3442
22	psycholog*	58469
23	MeSH descriptor: [Emotions] explode all trees	10387
24	emotion*	7899
25	anxi*	20388
26	MeSH descriptor: [Life Style] explode all trees	2365
27	"life style*" or lifestyle*	5086
28	MeSH descriptor: [Uncertainty] explode all trees	75
29	uncertaint*	8838
30	MeSH descriptor: [Attitude to Death] explode all trees	101
31	MeSH descriptor: [Attitude to Health] explode all trees	21982
32	attitude	11676
33	experience*	39675
34	#1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23 or #24 or #25 or #26 or #27 or #28 or #29 or #30 or #31 or #32 or #33	212836
35	MeSH descriptor: [Kidney Transplantation] explode all trees	3147
36	(kidney* or renal) and (transplant* or donor* or provider* or survivor*)	9940
37	#35 or #36	9940
38	cadaveric	692
39	#37 and #38	519
40	kidney* or renal	36166
41	#35 or #40	36166
42	MeSH descriptor: [Unrelated Donors] explode all trees	2
43	"unrelated donor*"	195
44	#42 or #43	195
45	#41 and #44	25
46	#39 or #45	542
47	MeSH descriptor: [Renal Replacement Therapy] explode all trees	7312
48	"renal replacement therap*" or RRT or "dialysis patient*"	1530

49	(renal or kidney) and dialysis	7982
50	hemodiafiltration	311
51	hemodialysis or HD	6993
52	"peritoneal dialysis" or PD	15327
53	hemofiltration	519
54	#47 or #48 or #49 or #50 or #51 or #52 or #53	28910
55	MeSH descriptor: [Kidney Failure, Chronic] explode all trees	3151
56	"end stage renal" or "end-stage renal" or ESRF or ESRD	1723
57	"chronic kidney"	1427
58	#55 or #56 or #57	4948
59	#54 or #58	30640
60	(#34 and #37 and #59)	1125
61	MeSH descriptor: [Living Donors] explode all trees	265
62	#60 not #61	1089
63	MeSH descriptor: [Empirical Research] explode all trees	358
64	"qualitative research" or "qualitative stud*"	1230
65	"interpretive research" or "interpretive stud*"	1
66	"critical research" or "critical stud*"	33
67	"qualitative descriptive"	15
68	"grounded theor*"	53
69	"case stud*"	1740
70	"action research"	209
71	ethnograph*	101
72	phenomenolog*	142
73	#63 or #64 or #65 or #66 or #67 or #68 or #69 or #70 or #71 or #72	3373
74	#60 and #73	31
75	#62 and #73	28
76	MeSH descriptor: [Waiting Lists] explode all trees	307
77	MeSH descriptor: [Watchful Waiting] explode all trees	77
78	wait*	5480
79	#76 or #77 or #78	5480
80	#60 and #79	88
81	#62 and #79	88
82	#74 and #79	15
83	#75 and #79	15

CINAHL search strategy

1. kidney failure
2. Renal Insufficiency
3. peritoneal dialysis
4. kidney transplantation
5. Renal Dialysis
6. haemodialysis
7. Kidney Disease
8. waiting list
9. quality of life
10. experience

11. adaptation
12. Attitude to Death
13. Attitude to Health
14. uncertainty
15. life change events
16. self care
17. self concept
18. self efficacy
19. interpersonal relations
20. activities of daily living
21. S1 or S2 or S3 or S4 or S5 or S6 or S7 or S8
22. S9 or S10 or S11 or S12 or S13 or S14 or S15 or S16 or S17 or S18 or S19 or S20
23. S21 and S22
24. S23 Narrow by Subject: - all adult

APPENDIX 3: SYSTEMATIC REVIEW APPRAISAL INSTRUMENTS

QARI appraisal instrument

JBI QARI Critical Appraisal Checklist for Interpretive & Critical Research

Reviewer _____ Date _____

Author _____ Year _____ Record Number _____

	Yes	No	Unclear	Not Applicable
1. Is there congruity between the stated philosophical perspective and the research methodology?	☐	☐	☐	☐
2. Is there congruity between the research methodology and the research question or objectives?	☐	☐	☐	☐
3. Is there congruity between the research methodology and the methods used to collect data?	☐	☐	☐	☐
4. Is there congruity between the research methodology and the representation and analysis of data?	☐	☐	☐	☐
5. Is there congruity between the research methodology and the interpretation of results?	☐	☐	☐	☐
6. Is there a statement locating the researcher culturally or theoretically?	☐	☐	☐	☐
7. Is the influence of the researcher on the research, and vice- versa, addressed?	☐	☐	☐	☐
8. Are participants, and their voices, adequately represented?	☐	☐	☐	☐
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	☐	☐	☐	☐
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	☐	☐	☐	☐

Overall appraisal: ☐ Include ☐ Exclude ☐ Seek further info. ☐

Comments (Including reason for exclusion)

_____

_____

_____

APPENDIX 4: SYSTEMATIC REVIEW DATA EXTRACTION INSTRUMENTS

QARI data extraction instrument

JBI QARI Data Extraction Form for Interpretive & Critical Research

Reviewer _____ Date _____

Author _____ Year _____

Journal _____ Record Number _____

Study Description

Methodology

Method

Phenomena of interest

Setting

Geographical

Cultural

Participants

Data analysis

Authors Conclusions

Comments

Complete Yes ☐ No ☐

Findings	Illustration from Publication (page number)	Evidence		
		Unequivocal	Credible	Unsupported

Extraction of findings complete Yes ☐ No ☐

APPENDIX 5: STUDIES EXCLUDED FROM THE SYSTEMATIC REVIEW

Moran A, Scott A, Darbyshire P. Waiting for a kidney transplant: patients' experiences of haemodialysis therapy. Journal of Advanced Nursing. [Research Support, Non-U.S. Gov't]. 2011 Mar;67(3):501-9.

Reason for exclusion: Study reported in "Moran A. The person's experience of end stage renal disease and haemodialysis therapy [Ph.D.]. Ann Arbor: Dublin City University (Ireland); 2008"

Murray LR, Conrad NE, Zarifian A. Perceptions of kidney transplant by persons with end stage renal disease/Research critique/Investigators' response. ANNA Journal. 1999;26(5):479-84+.

Reason for exclusion: Methodological quality score falls below the threshold of 14.6. Congruity between philosophical perspective and research methodology not stated, the researcher's cultural/theoretical perspective not stated and the influence of the researcher on the research and vice-versa not addressed.

Polaschek N. Living on dialysis: concerns of clients in a renal setting. Journal of Advanced Nursing. 2003;41(1):44-52.

Reason for exclusion: Study reported in "Polaschek N. The concerns of Pakcha men living on home haemodialysis: a critical interpretive study. Wellington: Victoria University of Wellington; 2000."

Wells SA. Occupational performance of Mexican Americans with end-stage-renal-disease living on dialysis in the lower Rio Grande Valley [Dr.P.H.]. Ann Arbor: The University of Texas School of Public Health; 2009.

Reason for exclusion: Methodological quality score falls below the threshold of 14.6. Lack of congruity between stated philosophical perspective and research methodology and between the research methodology, methods and interpretation of results. The researcher's cultural/theoretical perspective is not stated and the influence of the researcher on the research and vice-versa not addressed.

APPENDIX 6: TABLE OF FINDINGS EXTRACTED FROM STUDIES INCLUDED IN THE SYSTEMATIC REVIEW

Data extraction table				
Reference	**Calvey D, Mee L. The lived experience of the person dependent on haemodialysis. Journal of Renal Care. 2011 Dec;37(4):201-7.**			
Number	**Finding (verbatim from author)**	**Illustration from text and page number**	**Unequivocal/credible/ unsupported (U/C/Un)**	**Possible category**
1	An uncertain future	The enormity of life dependent on hemodialysis left the participants feeling as though there was no future ahead. They reported feelings of shock and fear, and finding themselves in a place of great uncertainty. pg 202 [Some] participants described experiences of having their future returned to them by dialysis … a lifeline to being alive. Pg 203	U	Uncertainty
2	Lost dreams. The loss of dreams introduced elements of sadness leading to anger and bitterness in the descriptions of perceived loss of planned future dreams	*M, "watching my children growing up and not being able to go out with them and show them what to do … I never did that with my children … something I would have liked to give them .. .not being able to do that, sort of irks me now".* Pg 203	U	Loss
3	Future hopes	Hope for the future lay mostly in the prospect of one day receiving a transplant and getting back to a normal life. The hope of receiving a kidney transplant was dominant in this study" Pg 203	U	Hope

4	Bodily self. Participants' descriptions of how they perceived themselves and the physical changes they had gone through	*J, "my skin changed … you feel dirty … no matter if you have a shower … I never feel clean"*. pg 204 The physical bodily change due to the placement of the HD access in this study, for some, brought distress. Pg 204	U	Body image
5	Mental self. Participant's perceptions of themselves leading to feelings of powerlessness, worthlessness and low self-confidence.	Strength and state of mind was thought to be of great importance. Pg 204 Depression was seen by the participants of this study as the outcome of not maintaining a positive outlook. … although they admitted feeling depressed at times, it certainly did not appear to be a leading concern. Pg 204	C	Mental health
6	Functional self. The impact on what participants perceived to be their normal routines and their varying roles in life.	*T, "you're basically working around the dialysis, like it's stuck in my head"* Pg 204 They saw their ability to do things hindered by the loss of three days from the week. The impact on functional self was more evident when the participants considered the negative effect on their ability to work, resulting in loss of wages and inability to be counted as reliable. Pg 204	U	Normal life/loss
7	Social self. The impact of HD on family and friends and the impact of family and friends on the lives of participants	*M' "Why did she marry me, if she married someone else she'd get out … she wouldn't be living this kind of life … how unfortunate she was"* Pg 204 Participants felt greatly restricted in terms of not having freedom to travel. Pg 204	U	Social life/community

		Many participants were finding it difficult becoming part of the social atmosphere, feeling alienated by things like fluid and dietary restrictions. Pg 204 Some participants felt a responsibility to keep up a good face …Thus as well as being strong for themselves they had to be strong and support their families. Pg 204		
8	Mortality and the fragility of life	*J "I really thought I was finished … I saw the blood drain from my body into this machine ... I saw my life's blood flow out, it was a shock an absolute shock."* Pg 205 The participants in this study conveyed a strong realisation that life is fragile and can be lost very quickly. Pg 205	C	Mortality
9	Mortality and the issue of transplantation	The issue of kidney transplantation provided hope for all the participants. Mike had not only faced his own mortality but spared thoughts for the kidney donors respectfully acknowledging that for him to receive such a gift meant somebody would be losing their life. Pg 205 *A "somebody is dead and I'm alive with their kidney … that doesn't seem right to me".*	U	Mortality
10	Growing/learning self	Participants described their experiences of commencing treatment, beginning with little or no knowledge of renal failure or dialysis, slowly acquiring a degree of knowledge and experience and becoming more	U	Knowledge

		adaptive to the changing routine. Pg 205		
Reference	**Dekkers W, Uerz I, Wils J-P. Living Well with End Stage Renal Disease: Patients' Narratives Interpreted from a Virtue Perspective. Ethic Theory Moral Prac. 2005 2005/11/01;8(5):485-506.**			
1	Gratitude – hope	… participants explicitly mentioned that getting on dialysis had saved their lives. Pg 496 Many felt grateful for the support they got from relatives and friends and for the care they got at the hospital. Pg 497 Hope is important … one participant intentionally tried to be optimistic, to hope for the best, to look on the bright side. For her hope also meant getting a kidney transplan.t Pg 497	U	Hope
Reference	**Hagren B, Pettersen I, Severinsson E, Lützén K, Clyne N. The haemodialysis machine as a lifeline: experiences of suffering from end-stage renal disease. Journal of Advanced Nursing. 2001;34(2):196-202.**			
1	Gaining a sense of existential optimism	Many [patients] experienced fear of what would happen if the HD did not work or if they could not get a new kidney. Pg 200 However waiting for kidney transplantation and not knowing when this would be was a profound cause of suffering. But for some the possibility of getting a new kidney gave hope.	C	Mortality/hope
Reference	**Herlin C, Wann-Hansson C. The experience of being 30-45 years of age and depending on haemodialysis treatment: a phenomenological study. Scandinavian Journal of Caring Sciences. 2010;24(4):693-9.**			
1	Total lack of freedom	The total lack of freedom was always present in the thoughts of the	U	Loss/future hope

		patients and they were forced to learn to live with it. The participants expressed that they did not live fully. Pg 695 *"In the future when I am transplanted I think I will have more freedom. Then I can do what I want … leave town … order a vacation without thinking of the need of HD"*		
2	Feelings of loneliness	Three … had lost a partner after they started in HD treatment. Finding a partner after they started on HD treatment was … hard. Five … [said] having a job was helping them to feel less lonely. Pg 696 *" …how do you say it? Should you say it at once? 'I'm going in HD treatment and waiting for a new kidney!' Or should you say it after a week or a month?* Pg 696 *"To work is something I think is very important …. It is the social side … that you get out … otherwise it would have been hard … if I had no work to go to"* Pg 696	U	Social life/loss
3	Being on the waiting list for a kidney transplantation	Being on the waiting list for many years and not knowing for how many years one had to wait was described as the worst part. Feelings of uncertainty because of not knowing if they would get a kidney or not were always on their mind. Pg 696 *"The future for me is a transplantation that I am waiting for, and then I hope that everything will work out fine"* Pg 697 Many were afraid of the surgery and … medications. Others were	C	Uncertainty/hope

		worried of complications … such as rejection. Pg 696 *"To be transplanted means that I have to go through another complicated surgery … and after that it is not for sure that it will work out"*		
Reference	**Kaba E, Bellou P, Iordanou P, Andrea S, Kyritsi E, Gerogianni G, et al. Renal nursing. Problems experienced by haemodialysis patients in Greece. British Journal of Nursing. 2007;16(14):868-72.**			
1	Uncertainty	Even though patients considered that their treatment was going well at that point, they all expressed some anxiety about potential problems that could arise or the prospect of premature death. Pg 870 *"This is a road with no return. You are walking in the path and there is only in front, there is no left, no right to go. Now I am trying a bit because my daughter-in-law is pregnant, and I have something nice to expect. I pray I can get a transplantation soon so I can relax for 5 or 6 years."* Pg 870 Although they had not yet received a transplant they were confident that they would do so and it would be successful, freeing them from dialysis. Pg 870	U	Mortality, anxiety, transplant gives hope for a normal life, uncertainty
Reference	**Landreneau KJ, Ward-Smith P. Perceptions of adult patients on hemodialysis concerning choice among renal replacement therapies. Nephrology Nursing Journal. 2007;34(5):513.**			
1	Knowledge	Knowledge regarding renal replacement therapy was obtained from a variety of sources. The most frequent source mentioned was … health	U	Knowledge/community

		care professionals, specifically the physician. Another frequent source mentioned was the transplant surgeon. The dialysis nurses also mentioned as a source. Pg 516 *"They asked me would you want a kidney transplant? And I said yes I would because I didn't want to do this all my life"* Pg 516 *"They told me about the risks … and it's just a risk between life and death. That's mostly what I know about it you know. They were nurses"* Pg 516 Much of the knowledge shared by participants revealed outdated and inaccurate medical information. Pg 516		
2	Choice	One must consider and incorporate the medically appropriate time to present the types of renal replacement therapies and the patient's option to choose. Pg 517 *"My choice was to have HD. And I am on the list for a kidney transplant, and I've been on the list for several years"* … participants knew about transplantation after they started dialysis and talked with their 'dialysis doctor' about transplantation. This may be a factor of different physician's opinions or philosophies concerning the promotion of different types of renal replacement therapies. Pg 517	U	Choice/uncertainty

Reference	Moran A. The person's experience of end stage renal disease and haemodialysis therapy [Ph.D.]. Ann Arbor: Dublin City University (Ireland); 2008.			
1	Waiting for a kidney: Living in hope	The hope of a kidney transplant provided the participants with the possibility of returning to a normal life in the future. In addition, it provided them with the strength to endure the experience of being a renal patient. The information received from healthcare professionals in relation to the average waiting time for a kidney transplant contributed to the participants' experience of living in hope. Pg 173 Seeing other patients being called for a transplant and leave the dialysis unit contributed to Danny's experience of hope. These patients served to reassure him that one day he would also be called for a transplant. Pg 174 *"You're living in hope [of getting a transplant], you just feel like it could be tomorrow, it could be a year from tomorrow, it could be any day…That's the way I think, it [the transplant] will happen but you have to wait."* Pg 176	U	Hope/knowledge
2	Waiting for a kidney: Uncertainty	The participants' accounts specifically conveyed how the information they had received from the healthcare team about the average waiting time for a kidney transplant contributed to their uncertainty. Pg 178 It is important to point out that the average waiting time for a kidney transplant is merely an estimate, and many patients wait well beyond this time frame. However, it seemed that several of the participants	U	Uncertainty

		interpreted the average waiting time to mean the "actual" waiting time for a kidney transplant. While this belief allowed the participants to live in hope as they initially waited for a kidney transplant, it did not sustain their hope in the long-term. When the participants either reached or exceeded the "expected" date for a kidney transplant, they became uncertain. Pg 178 *"I get days when just the thought of coming here…I could just turn the car around and drive off home and not bother…and you think well how come some people… I've seen them go and have a transplant and they're gone, and I'm still here. "Why am I still here? Why am I here? Sometimes I think maybe I'm going to be waiting a long time, I better just get used to the idea.* Pg 180 *"You just get to a stage where you think it's [the transplant] never going to happen…you go into the dialysis unit and you hear somebody was called [for a transplant] and you'd be delighted for them but still your heart would drop when it wasn't you."* Pg 181		
3	Waiting for a kidney: Being on hold	As a result of the experience of uncertainty, some participants were unable to contemplate possibilities in the future. Moreover, the limitations and restrictions imposed by HD therapy prevented them from performing many of the everyday activities they took for granted in the past. Consequently, the participants described their experience of being on hold while they waited for a kidney transplant. Pg 185	U	Impact of dialysis on life/uncertainty/loss

		The absence of a definite endpoint to the wait meant that David was unable to contemplate any possibilities for the future. Pg 187 Embedded in Jeff's account of being on hold was the fear of missing out on the call for a kidney transplant. *"You're on hold so you are…it's just a big waiting game now … waiting for that call [for a transplant]…you never leave the phone, you have the phone with you 24/7…"* Pg 188 He described his experience of waiting for a transplant as being held back in a time, which revolved around the repetitive regimen of dialysis therapy. Pg 188 *"My life is on hold…very, very much so…I can't plan anything, can't go anywhere…I'm waiting for the phone to ring…when are you going to get that call for a transplant"* Pg 189		
Reference	**Polaschek N. The concerns of Pakcha men living on home haemodialysis: a critical interpretive study. Wellington: Victoria University of Wellington; 2000.**			
1	Suffering from the symptoms of CRF and dialysis pg 204	Dialysis is supposed to remove the symptoms of CRF by replacing their renal function according to the dominant discourse. However, despite excellent treatment, all of these men reported some troubling symptoms while living on dialysis. Pg 204 General lack of energy … an altered sleep pattern … itching and restless legs … hypotension … general non-specific malaise. Pgs 205-206	U	Physical health

		Although these men suffered from a range of symptoms they generally tended to downplay them. The tendency to initially underestimate their symptoms probably reflects the fact that, as they live with the symptoms on an ongoing basis, they have become an aspect of their lives that are coped with in part by being “normalized”. Pg 207		
2	Negotiating the requirements of dialysis to fit their lifestyle and the limitations involved Pg 210	All of these men reported that it actually had a significant impact on their lifestyle. Pg 210 *"I jealously guard the in-between days, I hate them being taken away from me, I feel I've lost a day. It's my lifeline, but I want to have a normal life during the day"* Pg 212 All mentioned the inability to travel on holidays as the most obvious limitation caused by living on HD. Pg 213 For most of the men the negotiation required to integrate the requirements of renal replacement therapy into their weekly schedule not only influenced their regular pattern of living but also resulted in some alteration of their dialysis or other aspects of the treatment regimen in order to manage it in their lives. Pg 214	U	Impact on normal life/knowledge/travel
3	Experiencing life on dialysis as ongoing	The many hours of their lives taken up by the treatment were the obvious focus of their sense of enduring a life on dialysis. …most felt it was time wasted which they could better use for other activities. Pg 217	U	Loss (of time)

		"it feels like a waste of time, on dialysis the machine runs your life." Pg 218		
4	Uncertainty about the future	A developing understanding, contrary to the optimism of the professional viewpoint, of the limitations of the efficaciousness of dialysis as a therapy for CRF gave rise to a sense of uncertainty about the future. Pg 219 *"I often wonder how long you can do this for..' there seems almost no hope of a transplant; in my age bracket perhaps the chances lessen, there's a certain amount of urgency as you get older."* Pg 220 *"I might not have thought of going on if I had known that this would be the future, or come of at a certain point."* Pg 221	U	Uncertainty
5	The expectation of a transplant	…these men looked forward to a different event that would both break the routine and address their uncertainty. They coped with the ongoingness and uncertainty of living on dialysis through their hope of a kidney transplant. Pg 222 *"Dialysis is a stepping stone until you get the transplant."* Pg 222 Other than Mark and Owen the men showed almost no recognition of the degree of uncertainty about receiving a transplant, let alone any awareness of the potential problems with transplantation itself not only the possibility of the transplanted kidney failing to function for some reason but also the long term complications associated with	U	Hope

		transplantation such as increased risk of life threatening infections or cancers. Pg 223 They coped through their hope that life on dialysis did not have to be accepted as permanent but was rather provisional, because they would in the future receive a transplant to enable them to escape from dialysis. Pg 224		
6	Changing personal relationships	The men's accounts suggested that living on dialysis had affected their relationships with their families and friends. Generally they tended to emphasize the ordinary character of their relationships, such as the understanding of friends who accommodated their dialysis in planning social activities or the easy acceptance of their treatment by grandchildren playing around the machine while they were dialysing. Pg 226 …their relationship with their partners, all well established, remained strong, but had altered somewhat in character. Their wives had adapted their own lifestyles to be present in the house when the men were doing their treatment. Pg226 "*…terrific amount of teamwork, it's so much easier with some helping, much more pleasurable, quicker if you work as team.*" Pg 227 All of the men recognised some costs to their partners from them being on dialysis, whether in terms of limiting their own activities or the	U	Social life/ relationships/ dependence

		stress of having to cope with their husband's illness and its treatment. Pg 227		
7	Their new healthcare relationships	While affirmed in their autonomy in managing their own dialysis at home, their awareness of the limited support actually available to them indicated their dependence on renal staff. Pg 228 Although they felt positive about their relationship with health care professionals, these men were sensitive to any perceived lack of being fully informed about their condition, therapy or its effects. Sometimes they expressed a sense of having been misled by renal health professionals. Pg 230	U	Dependence/knowledge
8	Dependence on the dialysis machine	*"I'd feel the extra day, my body tells me I need the dialysis machine, I don't deviate, it's not worth your while."* Pg 231 However, despite this common strategy of seeking to manage their lives on dialysis by maintaining a strict therapeutic regimen, they are still regularly reminded, by residual symptoms, limitations in their ordinary lives caused by the therapeutic regimen and occasional unexpected events underlining the uncertainty of life on dialysis, of their dependence on the therapeutic regimen for their continued wellbeing. Pg 232	U	Dependence
Reference	**Rittman M, Northsea C, Hausauer N, Green C. Living with renal failure. ANNA Journal. 1993;20(3):327-31; discussion 32.**			
1	Maintaining hope	Patients described hope as a significant aspect of coping … having a	U	Hope/future

		transplant, to get a job again, yet to be discovered treatments that would help them continue to live. Pg 329 Suffering from the pain and disability of renal failure is attenuated by hope and sustains individuals in daily living. Pg 329		
Reference	**Sadala MLA, Bruzos GAdS, Pereira ER, Bucuvic EM. Patients' experiences of peritoneal dialysis at home: a phenomenological approach. Revista Latino-Americano Enfermagem. [Article]. 2012;20(1):68-75.**			
1	Facing the world of renal failure and dialysis treatment	They described their anguish in the face of death; and the perception that they were launched into an unknown and frightening world, without escape. The treatment proposed by the healthcare team was the only way to survive but, in practice, it appeared painful and aggressive, drastically limiting their activities and social life. In addition, it would last for a long and unpredictable time, until an unlikely kidney appeared to have a transplant. Pg 71 Forced changes encompassed the whole organization of their world, involving their home, job, social gatherings. Additionally, they financially affected the family: they had to leave or change their job. Pg 72 The young revealed hope in soon having a kidney transplant: dreaming of a future free from catheters, from bags and from the dialysis machine: "*Well, what was more important to me was when I Joined the transplant waiting list to have an organ from a corpse. And I'm*	U	Impact on life/loss of freedom/hope

		waiting." Pg 72		
Reference	**Shih LC, Honey M. The impact of dialysis on rurally based Māori and their whānau/families. Nursing Praxis in New Zealand. 2011;27(2):4-15.**			
1	Stress from HD	Some participants admitted to reduced adherence to advised therapeutic regimens because of the costs of care. Pg 7 Most participants could not maintain employment because of their poor health and the need for dialysis. Pg 7 Participants and their families found the dialysis regimens and associated travelling stressful. Pg 7 *"You miss out on a lot of things you used to do in the past. You lose your social life, you can't go visiting or go away." Pg 7* While being on the transplant list resulted in hope for participants, the consequences of long waiting times and perhaps not receiving a kidney transplant were very stressful. Pg 7 *"I tried hard to keep up on the waiting list for many years; I feel aggravated sometimes. I have been on the transplant list for many years and nothing happened. I hope the next one may be me but I am always disheartened"* Pg 7 Being on the kidney transplant list was found to bring hope; however the long wait for a kidney transplant is a stressful process. Pg 8	U	Effect of dialysis on life/hope/uncertainty
Reference	**Yu H, Petrini MA. The HRQoL of Chinese patients undergoing haemodialysis. Journal of Clinical Nursing. 2010;19(5-6):658-65.**			

1	Psycho-social aspect: Anxiety	Among [the patients waiting for a kidney transplant], the longest waiting time was nearly five years. All of them showed different level of anxiety when they talked about transplantation. Pg 662 *"I do not know how long I will have to wait, I have heard of some who had to wait more than eight years. I cannot imagine having to wait so long…I get upset and lose my temper when I think of that. But who can tell me how long I will have to wait? I am really worried about that".* Pg 662	U	Uncertainty

APPENDIX 7: QUALITATIVE DESCRIPTIVE STUDY LETTER OF INVITATION TO PARTICIPATE

Date

Dear,

You are currently on dialysis under the care of a nephrologist at … *hospital* and are listed on the renal transplant waiting list.

Our department is participating in research about experiences of patients on the kidney transplant waiting list; I would like to invite you to attend a focus group to discuss the experiences of patients who are waiting for a kidney transplant. We are interested in finding out how people cope with waiting and what impact it has on their day to day lives. A participant information sheet and consent form is enclosed.

The focus group will be held on *date/time* at *location* and will take about 1 ½ hours.

If you would like to participate please return the signed consent form in the reply paid envelope.

Please telephone *name, Transplant co-ordinator, phone number* if you have any further questions

Yours sincerely,

Name

Director, Renal Department, St George Public Hospital

APPENDIX 8: QUALITATIVE DESCRIPTIVE STUDY PARTICIPANT INFORMATION SHEET

PARTICIPANT INFORMATION SHEET AND CONSENT FORM

The experiences of patients waiting for a kidney transplant

Invitation

You are invited to participate in a research study into the experiences of patients who are waiting for a kidney transplant.

The study is being conducted by: *name*

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

1. **'What is the purpose of this study?'**

The purpose is to investigate the effect of waiting for a kidney transplant on patients' day to day lives and how they feel about it.

2. **'Why have I been invited to participate in this study?'**

You are eligible to participate in this study because you are on dialysis and you are on the kidney transplant waiting list.

3. **'What if I don't want to take part in this study or if I want to withdraw later?'**

Participation in this study is voluntary. It is up to you whether or not you participate. If you decide not to participate, it will not affect the treatment you receive now or in the future. Whatever your decision, it will not affect your relationship with the staff caring for you.

If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason. However, it may not be possible to withdraw your data from the study results if these have already had your identifying details removed.

4. **'What does this study involve?'**

If you agree to participate in this study, you will be asked to sign the participant consent form.

If you agree to participate in this research, you will then be asked to attend a focus group at *location* on the following *dates and times* ….to talk about your experiences of waiting for a kidney transplant. The focus group will take approximately 90 minutes and will be recorded in order to accurately capture all your responses.

5. **'How is this study being paid for?'**

There is no sponsorship for this study and the work is being undertaken in the investigator's own time.

6. **'Are there risks to me in taking part in this study?'**

You may find it distressing to discuss your feelings about dialysis and transplantation. Should you find the discussion distressing renal social worker will be available for support and counselling.

7. **'Will I benefit from the study?'**

This study aims to further medical knowledge and may improve future treatment of patients who are waiting for a kidney transplant; however it may not directly benefit you. Participation in the study will have no impact on your wait for a transplant.

8. **'How will my confidentiality be protected?'**

Any identifiable information that is collected about you in connection with this study will remain confidential and will be disclosed only with your permission, or except as required by law. All data will be stored in secure files for 5 years and then destroyed.

9. **'What happens with the results?'**

If you give us your permission by signing the consent document, we plan to use the research to learn more about how we can better support patients who are waiting for a kidney transplant.

10. 'What should I do if I want to discuss this study further before I decide?'

When you have read this information, the researcher *name* will discuss it with you and any queries you may have. If you would like to know more at any stage the contact number is …

11. 'Who should I contact if I have concerns about the conduct of this study?'

This study has been approved by the Human Research Ethics Committee of the *district.* Any person with concerns or complaints about the conduct of this study should contact the Research Support Office on *number*, or email *address* and quote *reference number*.

Thank you for taking the time to consider this study.

If you wish to take part in it, please contact *name, phone number*

This information sheet is for you to keep.

APPENDIX 9: QUALITATIVE DESCRIPTIVE STUDY PARTICIPANT CONSENT FORM

CONSENT FORM

The experiences of patients waiting for a kidney transplant

1. I, _____

of _____

agree to participate in the study described in the participant information statement set out above.

2. I acknowledge that I have read the participant information statement, which explains why I have been selected, the aims of the study and the nature and the possible risks of the investigation, and the statement has been explained to me to my satisfaction.

3. Before signing this consent form, I have been given the opportunity of asking any questions relating to any possible physical and mental harm I might suffer as a result of my participation and I have received satisfactory answers.

4. I understand that I can withdraw from the study at any time without prejudice to my relationship to the … *Hospital* Renal Department or my medical attendants.

5. I agree that research data gathered from the results of the study may be published, provided that I cannot be identified.

6. I understand that if I have any questions relating to my participation in this research, I may contact *name* on telephone … who will be happy to answer them.

7. I acknowledge receipt of a copy of this Consent Form and the Participant Information Statement.

Complaints may be directed to the Research Ethics Secretariat, South Eastern Sydney Local Health District – Northern Sector, Prince of Wales Hospital, Randwick NSW 2031 Australia (phone 02-9382 3587, fax 02-9382 2813, email ethicsnhn@sesiahs.health.nsw.gov.au.

Signature of participant	**Please PRINT name**	**Date**
Signature of witness	**Please PRINT name**	**Date**
Signature of investigator	**Please PRINT name**	**Date**

APPENDIX 10: QUALITATIVE DESCRIPTIVE STUDY REVOCATION OF CONSENT FORM

REVOCATION OF CONSENT

The experiences of patients waiting for a kidney transplant

I hereby wish to **WITHDRAW** my consent to participate in the study described above and understand that such withdrawal **WILL NOT** jeopardise any treatment or my relationship with the … *Hospital* Renal Department or my medical attendants.

Signature of participant **Please PRINT name**

Date

_____ _____ _____

The section for Revocation of Consent should be forwarded to:

Name, address

APPENDIX 11: QUALITATIVE DESCRIPTIVE STUDY ETHICS APPROVAL LETTER

NSW GOVERNMENT Health
South Eastern Sydney Local Health District
HUMAN RESEARCH ETHICS COMMITTEE
Room G71 East Wing
Edmund Blacket Building
Prince of Wales Hospital
RANDWICK NSW 2031
Tel: 02 9382 3587 Fax: 02 9382 2813
http://www.seslhd.health.nsw.gov.au/POWH/researchsupport/default.asp

12 April 2013

Mrs Tania Burns
Renal Transplant CNC
Renal Department
St George Hospital
KOGARAH NSW 2217

Dear Mrs Burns

HREC ref no: 12/247 (LNR /12/POWH/467)
Project title: Quality of life of patients on dialysis and awaiting a cadaveric renal transplant

Thank you for submitting the above Low/Negligible Risk Application for review by the Human Research Ethics Committee (HREC). Based on the information you have provided and in accordance with the NHMRC guidelines [National Statement 2007 – Section 5 Institutional Responsibilities and "*When does quality assurance in health care require independent ethical review?*" (2003)], this project has been assessed as low risk and is therefore exempt from full HREC review.

The project was considered by the HREC Executive Committee on 19 November 2012. The Committee asked for clarification of certain matters/modifications and delegated authority to grant final approval to the Executive Officer.

I am pleased to advise that with your correspondence dated 10 April 2013 the requested information and revised documents were received incorporating the recommendations of the Executive. Ethical approval has been granted for the above project to be conducted at:

- St George Hospital

The following documentation has been approved:

- Low/negligible risk application, submission code AU/6/7791115, dated 11 March 2013
- Participant Information Sheet and Consent Form, version 2, dated 11 March 2013
- Participant Invitation Letter, dated April 2013

Conditions of approval

1. This approval is valid for 5 years from the date of this letter.
2. Annual reports must be provided on the anniversary of approval.

Prince of Wales Hospital
Community Health Services
Barker Street
Randwick NSW 2031

3. A final report must be provided at the completion of the project.
4. Proposed changes to the research protocol, conduct of the research, or length of approval will be provided to the Committee.
5. The Principal Investigator will immediately report matters which might warrant review of ethical approval, including unforeseen events which might affect the ethical acceptability of the project and any complaints made by study participants.

Optional It is the responsibility of the sponsor or the principal (or co-ordinating) investigator of the project to register this study on a publicly available online registry (eg Australian New Zealand Clinical Trials Registry www.anzctr.org.au).

For NSW Public Health sites only: You are reminded that this letter constitutes ethical approval only. You must not commence this research project until you have submitted your Site Specific Assessment (SSA) to the Research Governance Officer of the appropriate institution and have received a letter of authorisation from them.

Should you have any queries, please contact the Research Support Office on (02) 9382 3587. The HREC Terms of Reference, Standard Operating Procedures, membership and standard forms are available from the Research Support Office website:
http://www.seslhd.health.nsw.gov.au/POWH/researchsupport/default.asp.

Please quote **HREC ref no: 12/247** in all correspondence. We wish you every success in your research.

Yours sincerely

Deborah Adrian
Executive Officer, Human Research Ethics Committee

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research (2007)*, NHMRC and Universities Australia *Australian Code for the Responsible Conduct of Research (2007)* and the *CPMP/ICH Note for Guidance on Good Clinical Practice*.

APPENDIX 12: COREQ CHECKLIST

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	70
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	70
Occupation	3	What was their occupation at the time of the study?	70
Gender	4	Was the researcher male or female?	68
Experience and training	5	What experience or training did the researcher have?	70
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	65
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	65
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	64-65
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	64
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	67
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	66
Sample size	12	How many participants were in the study?	67
Non-participation	13	How many people refused to participate or dropped out? Reasons?	67
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	69
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	72
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	74-75
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	70
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	N/A f/groups
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	70
Field notes	20	Were field notes made during and/or after the inter view or focus group?	70
Duration	21	What was the duration of the inter views or focus group?	169
Data saturation	22	Was data saturation discussed?	103-104
Transcripts returned	23	Were transcripts returned to participants for comment and/or	N/A f/groups

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	72
Description of the coding tree	25	Did authors provide a description of the coding tree?	76
Derivation of themes	26	Were themes identified in advance or derived from the data?	71
Software	27	What software, if applicable, was used to manage the data?	71
Participant checking	28	Did participants provide feedback on the findings?	74
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	76-94
Data and findings consistent	30	Was there consistency between the data presented and the findings?	76-94
Clarity of major themes	31	Were major themes clearly presented in the findings?	76-91
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	92-94

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.